

# Evaluation Report

An Evaluation of Living it Up, a Self-Management  
Hub for those aged over 50 with a Long-term  
Condition/s and/or Carers'

by Impact Generation

April 2016



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## Citation for this report

When citing the findings from this report, please use the following citation:

*'Evaluation of Living it Up, a self-management hub for those aged over 50 with a long-term condition/s and carers' by Impact Generation: The Home of Behaviour Change (April 2016)*

## 1.0 Introduction

### 1.1 The purpose of this report

This report presents an evaluation of 'Living it Up' (LiU), which is an initiative developed in Scotland whose exploratory development in the first three years was co-funded by The Scottish Government and InnovateUK. It is now solely funded by The Scottish Government.

### 1.2 About Living it Up

LiU is a developing digital self-care hub, targeted at those aged over 50 years old who live with long-term conditions and/or carers in Scotland. LiU is led by NHS24 in Scotland and has been developed collaboratively with inputs from many health, care, industry, third sector and academic partners including:

- The Scottish Government
- InnovateUK
- Highlands & Islands Enterprise
- Scottish Enterprise
- Carers Scotland
- Highland Health Care
- NHS Forth Valley
- NHS Western Isles
- NHS Lothian
- Moray Community Health and Social Care Partnership
- Intrelate
- Storm Health
- Digital Life Sciences
- The Health and Social Care Alliance
- Ernst and Young
- ATOS
- Sitekit
- Maverick TV
- Glasgow School of Art
- Looking local
- Phillips

During its development, exploratory phase LiU explored digital innovations as a way of supporting over 50s to self-care and self-manage with a particular focus on carers and

those living with long-term conditions in Scotland. In doing so, LiU aims to support a myriad of long-term condition health and care strategies, quality strategies and health inequality reduction in Scotland, technology enabled care, and health.

### 1.3 Aim and objectives of 'LiU'

#### 1.3.1 Overall aim of Living it Up

The overall aim of 'LiU' is:

*'To develop and deliver a digitally enabled, thriving community that provides holistic opportunities to support better health, wellbeing and active lifestyles in Scotland. The initiative is aimed at people over the age of 50, with particular interest to carers, and people living with long term health conditions<sup>1</sup>'*

Within this overall aim the following attendant objectives were set:

- To better connect people to their support circle (including family, friends, informal support and health and care professionals);
- To enable and motivate people to use technology to improve their health and wellbeing; and,
- To empower people to be confident contributors to the Living it Up community, sharing their experiences and knowledge.

#### 1.3.2 The Living it Up service

LiU is an online self-management hub that aims to inspire and help people to improve their health and wellbeing<sup>2</sup>. Its services are currently active in five areas across Scotland: Forth Valley, Highland and Argyll & Bute, Lothian, Moray, and the Western Isles, with two more health and care partnership areas having more recently come on board<sup>3</sup>.

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<sup>1</sup> LIVING IT UP, 2015. *About Us*. [online]. Glasgow: NHS24. Available from: <https://portal.livingitup.org.uk/page/about-us#> [Accessed 16 March 2016].

<sup>2</sup> LIVING IT UP, 2015. *About Us*. [online]. Glasgow: NHS24. Available from: <https://portal.livingitup.org.uk/page/about-us#> [Accessed 16 March 2016].

<sup>3</sup> LIVING IT UP, 2015. *About Us*. [online]. Glasgow: NHS24. Available from: <https://portal.livingitup.org.uk/page/about-us#> [Accessed 16 March 2016].

By using familiar technology like computers, tablets and smartphones, users of LiU are enabled to access innovative and trusted health, care and wellbeing services, local information volunteering opportunities, interactive tools to support self-care and be sign-posted to join peer support groups<sup>4</sup>.

LiU is focused on working collaboratively with its communities. Each stage of LiU's development was informed by a combination of community engagement and input from technology experts, plus health and care staff in the five geographic areas.

## 1.4 Evaluating Living it Up

Impact Generation was appointed to develop and deliver a robust evaluation for LiU.

### 1.4.1 The primary objectives for the evaluation

The primary objectives of the evaluation were to determine levels of:

1. Behaviour change;
2. Impact on health and wellbeing outcomes;
3. Ease of Access; and,
4. Return on investment.

The objectives for the study meant undertaking three types of evaluation. These were:

- **Evaluation one:** used an accredited theory of change approach to determine what (if any) behaviour change and health and wellbeing impact LiU generated;
- **Evaluation two:** was to determine ease of access that LiU presented using industry standard guidelines for development of online public services to determine the accessibility of LiU to the public; and
- **Evaluation three:** was to use the primary research gathered within evaluation one and extrapolate material significance from that research to determine a Return on Investment for LiU.

In addition, readers are also reminded that findings in this cohort study are indicative. This is due to several restrictive factors that affected the scale of the study, including: scope/research objectives set for the evaluation, design, sample size, budget and time.

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<sup>4</sup> LIVING IT UP, 2015. *About Us*. [online]. Glasgow: NHS24. Available from: <https://portal.livingitup.org.uk/page/about-us#> [Accessed 16 March 2016].

## 2.0 METHOD

This chapter explains the methods used to conduct LiU's three evaluations.

1. **Evaluation one:** used a valid theory of change approach to determine what (if any) behaviour change and health and wellbeing impact LiU generates;
2. **Evaluation two:** gauged the ease of access of LiU using industry standard tools and guidelines that are used for the development of governmental online public services; and,
3. **Evaluation three:** was to use the primary research gathered within evaluation one to extrapolate material significance from that research to determine a Return on Investment calculation.

### 2.1 Primary objectives

The primary objectives of the evaluation study were to determine what (if any) levels of:

1. Behaviour change;
2. Impact on health and wellbeing outcomes;
3. Ease of Access; and,
4. Return on Investment;

that active users of LiU aged 50 or over with a long-term condition and/or carers experience.

### 2.2 Secondary objectives

Specifically, the secondary objectives or terms of reference that were agreed for the evaluation were to:

- Gauge and determine evidence (if any) for behaviour change and impact when regularly using LiU;
- Gauge and determine evidence (if any) regarding the degree of accessibility (according to WC3 industry standards for digital services<sup>5</sup>) that LiU provides;

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<sup>5</sup> Services that HM Government provide are for the benefit of all citizens of the United Kingdom. No user should be excluded on the basis of disability. To do so would breach the Equality Act 2010. Digital services must therefore comply with legal requirements and meet Government Level AA of the Web Content Accessibility Guidelines (WCAG) 2.0 and W3C standards that provide a range of Accessibility Evaluation Resources. THE UK GOVERNMENT, 2014. *Accessibility*.

- Assess and determine evidence (if any) regarding the level of support LiU provides to active users and, identify if possible, at what stage/s or tipping points LiU is used;
- Determine the extent that LiU supports active users of the digital service when managing their LTCs and/or caring duties;
- Measure the impact/s (at individual and aggregate level) for any changes in self-care and self-management for health and wellbeing;
- Understand what (if any) increase in access to health and social care services LiU may take place;
- Calculate potential economic savings that LiU provides to society by determining an attributable Social Return on Investment (SROI);
- Set up an evaluation model that can be used over the next three years; and,
- Provide a statement about how evidence-based analytics helps to improve health and well-being.

## 2.3 Evaluation participants

For the purposes of recruiting respondents into the evaluation and analysis, active users of LiU were defined as:

- Managing a long-term condition for 1-year or more; and,
- Using LiU twice or more a month to help to support how they care for their long-term condition and/or caring duties (LiU's online and/or community service).

## 2.4 A Principled approach for Living it Up's evaluation

### 2.4.1 Principles of self-management used to inform the evaluation

Principles *proposed by the Long Term Conditions Association in Scotland (LTCAS) in its 2009 Guidance Gaun Yersel*<sup>6</sup> provide the substance behind much government thinking and policy in Scotland. Largely, these de-emphasise a reliance on medical interventions, preferring a shift towards health and care environments that are clinical, self-directed and managed as well as therapeutic<sup>7</sup>.

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*How to make services that everyone can use.* [online]. London: The UK Government. Available from: <https://www.gov.uk/service-manual/user-centred-design/accessibility> [Accessed February 2016].

<sup>6</sup> NHS SCOTLAND, 2009. Long Term Conditions Collaborative: Improving Self Management Support. [online]. Edinburgh: The Scottish Government. Available from: <http://www.gov.scot/resource/doc/274194/0082012.pdf> [Accessed February 2016].

<sup>7</sup> NHS SCOTLAND, 2009. Long Term Conditions Collaborative: Improving Self Management Support. [online]. Edinburgh: The Scottish Government. Available from: <http://www.gov.scot/resource/doc/274194/0082012.pdf> [Accessed February 2016].

Development of the research instruments for the primary research (depth interview discussion guides, vignettes, online survey and diary) were therefore based upon these principles. Written in the first person, the three 'GauN Yersel' principles are:

- "Evaluation should be on-going and shaped by my experience. They should be non-judgmental and focus on more than medical outcomes";
- "Self-management does not mean managing my long-term condition alone. It's about self determination in partnership with supporters"; and,
- "I am involved in my own care. Those who care for me and organisations that represent me, shape new approaches to my care".

## 2.5 Evaluation approach and methods

### 2.5.1 Research approach

For evaluations one and three, i.e. to determine what (if any) behaviour change and impact LiU may generate and, to supply data for the calculation of a SROI for LiU, the primary research was designed using a Theory of Change (TOC) approach<sup>8</sup> and was structured as a cohort study<sup>9</sup>. SROI calculations can only be undertaken using a TOC and it is also best practice to determine behaviour change and impact using a TOC.

For evaluation two i.e. to determine the level of accessibility of LiU, online governmental service design guidelines within the WC3 developer toolkit were used for the assessment.

#### *Validity of evidence using a Theory of Change*

Theory of Change (ToC) is a validated, best practice approach recommended by National Institute for Clinical Excellence<sup>10</sup> (NICE) and The Health Foundation: Make Change Work paper (March 2016)<sup>11</sup>. TOC is also supported by key institutions in care and government.

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<sup>8</sup> BURD, H. and HALLSWORTH, M., 2016. *Making the change: Behavioural factors in person- and community-centred approaches for health and wellbeing*. [online]. London: Nesta. Available from: [http://www.nesta.org.uk/sites/default/files/making\\_the\\_change.pdf](http://www.nesta.org.uk/sites/default/files/making_the_change.pdf) [Accessed March 2016].

<sup>9</sup> UNIVERSITY COLLEGE LONDON, 2015. *Cohort Studies*. [online]. London: University College London. Available from: <https://www.ucl.ac.uk/ich/research/population-policy-practice/research/approaches/cohort-studies> [Accessed February 2016].

<sup>10</sup> NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE), 2007. *Behaviour change: general approaches*. London: NICE (2007). P. 1-18

<sup>11</sup> BURD, H. and HALLSWORTH, M., 2016. *Making the change: Behavioural factors in person- and community-centred approaches for health and wellbeing*. [online]. London: Nesta. Available from: [http://www.nesta.org.uk/sites/default/files/making\\_the\\_change.pdf](http://www.nesta.org.uk/sites/default/files/making_the_change.pdf) [Accessed March 2016].

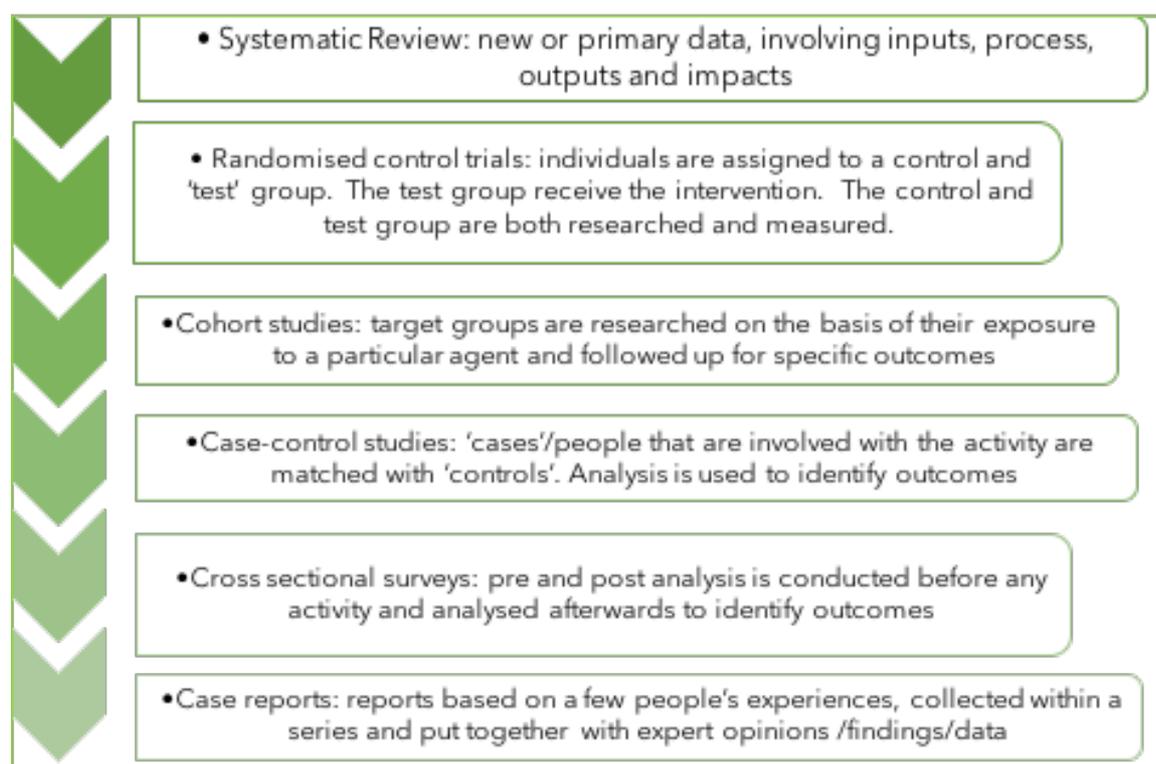
Therefore all primary research tools and analysis in evaluations one and three used a Theory of Change approach<sup>12</sup> as well as the principles of long-term condition self-care and self-directed supported noted in 'Gaun Yersel'.

### *Reliability of evidence captured using a cohort study*

Cohort studies are highly ranked in Petticrew and Roberts (2006) Hierarchy of Evidence<sup>13</sup>. The Hierarchy of Evidence ranks evidence based on tested reliability for detecting social change. If the 'Hierarchy of Evidence' is applied to the LiU evaluation, the cohort study is ranked one-step below the credibility of a randomised control trial. See diagram 1.1 next.

Diagram 1.1 Hierarchy of Evidence, Pettigrew and Roberts (2006)

#### HIGHER LEVELS OF EVIDENCE RELIABILITY



#### LOWER LEVELS OF EVIDENCE RELIABILITY

<sup>12</sup> NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE), 2007. *Behaviour change: general approaches*. London: NICE (2007).

<sup>13</sup> PETTICREW, M. and ROBERTS, H., 2006. *Systematic Reviews in the Social Sciences: A Practical Guide*. Oxford: Blackwell Publishing.

## *Cohort studies*

A cohort study is usually composed of two or more samples (groups of respondents) where one group is exposed to 'an active ingredient' and the other group is not. When both samples are monitored and studied over a period of time, difference/s may emerge and be detected between the two samples in an evaluation.

In reference to the objectives of the evaluation for LiU therefore, it meant that the study team could detect what (if any) behaviour change or outcome/s as well as any impact could be attributed to LiU, where LiU acted as the active ingredient.

From hereon in, the group exposed to LiU is termed as active users or known as the intervention group. Whereas the group that has no connection and/or does not use LiU is termed as non-users or the control group.

### **2.5.2 Minimising bias in the study**

Bias was limited in the cohort study by undertaking the following:

- Independent recruitment of both the intervention and control study samples by an external agency
- Using a cohort study approach that has a high position in the Hierarchy of Evidence (Pettigrew and Roberts 2006)
- Using only best practice research methods and approaches recommended in guidance Social Research Association to conduct LiU's cohort study<sup>14</sup>
- Gathering sufficient amounts of data in order to conduct statistical analysis regarding outcome findings
- Differing teams within Impact Generation conducted the research with the control and intervention samples
- An independent review undertaken by a statistician, Donal McDade from Social Market Research as per Social Research Association Guidance<sup>15</sup>
- An independent review undertaken by a Dr of Psychology, Dr Dennis McCoy, formerly of Queens University<sup>16</sup>

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<sup>14</sup> Social Research Association (June 2015) Available at: <http://the-sra.org.uk/wp-content/uploads/what-is-high-quality-social-research.pdf>, 'Independently validated', P.1

<sup>15</sup> Social Research Association (June 2015) Available at: <http://the-sra.org.uk/wp-content/uploads/what-is-high-quality-social-research.pdf>, 'Independently validated', P.1

<sup>16</sup> Social Research Association (June 2015) Available at: <http://the-sra.org.uk/wp-content/uploads/what-is-high-quality-social-research.pdf>, 'Independently validated', P.1

### 2.5.3 Independent recruitment of participants

To minimise bias, an independent recruitment firm was used to recruit participants aged over 50 with a long-term condition/s and/or carer in Scotland into two cohorts.

Participants were recruited into intervention and control groups, with both samples dispersed across geographical area socioeconomic group, gender and nationality as well as nature of long-term conditions in Scotland.

Participants were drawn from the five geographical areas involved in LiU, namely: NHS Highland; NHS Western Islands; NHS Forth Valley; NHS Lothian and NHS Moray.

A total of 39 respondents were recruited into the two groups at the outset. Where feasible, age, gender, caring relationships and health condition were also matched by the recruitment firm to provide as an accurate comparison as possible.

#### *Intervention group recruitment*

For the intervention group, participants were recruited in September and October 2015 on the basis of being an active user of LiU i.e. using LiU twice or more a month and managing a long-term condition for one year or more. Users in this group were placed in one cohort and studied over the 2-month period.

This sample was recruited via an email invite issued to 'active users' via the LiU's online service. A total of 22 respondents opted-in at that initial recruitment stage and formed the intervention group sample.

Opt-in respondents were then screened according to how long they had been managing their LTC/s and how regularly and the length of time that they had been using LiU. Where possible, recruits were also recruited on the basis of rural, urban and island communities. The screening process yielded 17 respondents for the intervention group.

See table 1.0 for a breakdown of the participants recruited into the intervention group.

Table 1.0 Participants recruited into the intervention group listed by nature of long-term condition and geographical determinant.

Alias	Intervention/Control	Condition/Carer	Urban/Rural
IU1	Intervention	LTC - COPD	Urban
IU2	Intervention	Carer	Urban

IU3	Intervention	LTC - M.S	Urban
IU4	Intervention	Carer	Urban
IU5	Intervention	LTC - High Blood Pressure, Asthma	Urban
IU6	Intervention	Carer	Urban
IU7	Intervention	LTC - Sarcoidosis, Thyroid	Urban
IU8	Intervention	LTC - COPD	Urban
IU10	Intervention	LTC - Lung Transplant	Urban
IR1	Intervention	LTC - Arthritis	Rural
IR2	Intervention	LTC - Diabetic	Rural
IR3	Intervention	LTC - Walking Problems	Rural
IR4	Intervention	LTC - Diabetic	Rural
IR5	Intervention	Carer	Rural
IR7	Intervention	LTC - Diabetic	Rural
IR8	Intervention	LTC - Auto Immune System	Rural
IR9	Intervention	LTC - Arthritis	Rural

### *Control group recruitment*

Respondents in the control group were recruited in October 2015. This group was over-recruited due to the likelihood of their attrition in the study due to them typifying hard to engage respondents.

This sample was recruited on the basis of 'matching' the LTC and carer profile achieved in the intervention group, as well as matching geographical locations, as far as possible.

Users in this group were placed in the second cohort and studied over a 2-month period.

Recruitment of the control sample initially yielded 22 respondents. However, by the end

of the study period, 6 participants in the control group opted out of the evaluation. Reasons given for their opt-out were ill-health, unplanned hospitalisation and/or being unwilling to sustain the diary exercise. This meant 16 control respondents sustained the diary and telephone interview research.

See Table 2. for a breakdown of the participants recruited into the control group listed by nature of long-term condition and geographical location.

Table 2. Participants recruited into the control group listed by nature of long-term condition and geographical condition

Alias	Intervention/Control	Nature of respondent Long-term Condition (LTC)/Carer	Geographical location
CU1	Control	LTC - COPD	Urban
CU2	Control	LTC - Diabetic	Urban
CU4	Control	LTC - Asthma	Urban
CU6	Control	LTC - Multiple Sclerosis	Urban
CU7	Control	Carer	Urban
CU8	Control	LTC - Mental Health, Arthritis	Urban
CU9	Control	LTC - Heart Condition, Bowel Issues	Urban
CU11	Control	LTC - Arthritis, Mental Health	Urban
CR2	Control	LTC - Heart Condition	Rural
CR3	Control	LTC - Diabetes	Rural
CR4	Control	Carer	Rural
CR6	Control	LTC - Asthma/Diabetic	Rural
CR7	Control	LTC - High Blood Pressure	Rural
CR8	Control	LTC - Heart Condition	Rural
CR9	Control	LTC - Asthma	Rural

CR11	Control	Carer	Rural
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#### 2.5.4 Level of engagement of the samples within the evaluation

The table below documents the level of engagement of respondents recruited in both samples for the intervention and control groups.

Table 3. Respondents engaged within the cohort study

Type of Engagement	Control	Intervention	Total
No. of total participants independently recruited	22	17	39
No. of Participants with Long-term conditions	13	13	26
No. of Carer Participants	3	4	7
Respondent attrition/loss during study due to ill-health	6	0	6
No. of 1-Week Diaries Returned in Study Period	101	116	217
No. Interviewed by Telephone	9	10	19
No. of Data Points Collected within Study	11,850	13,588	25,438
Unprompted Mentions of LiU Diarised	0	5	5

#### 2.5.5 Level of engagement by participants in the evaluation study

Whilst the number of participants in the cohort study were modest (which was by design due to the large evaluation scope as well as budget and time available), the mixed methods used within the primary research over a continuous 2-month period yielded over 25,000 points of data within the cohort study.

## 2.6 Research methods

### 2.6.1 A mixed method approach

A mixed method approach was used for the three evaluations consisting of quantitative and qualitative research.

However, readers are invited to note that this report examines the findings from the primary research involving end-user beneficiaries of LiU only.

Findings from the secondary desk report are appended separately in Appendix B and findings from the quantitative survey regarding practitioner change will be delivered as an addendum to this report in May 2016. This allows the survey research to be up-scaled to ensure greater representation of care and health practitioners across each of the geographical area to participating.

The primary and secondary research is now briefly described.

### 2.6.2 Secondary research: desk research

In order to understand what approach, research design and findings would be appropriate to detecting behaviour change, impact, accessibility for LiU in the primary research, the evaluation team first conducted a desk research exercise.

The desk research exercise reviewed the latest long-term conditions guidance, policy and the measurement of behaviour change advice. Including, long-term conditions, Scottish Government's 2020 Vision: National Action Plan for Long-term Conditions (2009)<sup>17</sup> and older people's quality of life policy context in Scotland<sup>18</sup>.

In addition, the desk research reviewed a large sample of secondary and grey data collected over LiU's development.

#### *Defining the measurement of behaviour change*

Based on the findings of the desk research exercise, Impact Generation used the National

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<sup>17</sup> THE SCOTTISH GOVERNMENT, 2009. Improving Health and Wellbeing of People with Long Term Conditions in Scotland: A national Action Plan. [online]. Edinburgh: The Scottish Government. Available from: [http://www.sehd.scot.nhs.uk/mels/CEL2009\\_23.pdf](http://www.sehd.scot.nhs.uk/mels/CEL2009_23.pdf) [Accessed February 2016].

<sup>18</sup> COHEN, L. et al., 2014. *Optimising Older People's Quality of Life: an Outcomes Framework. Strategic Outcomes Model*. Edinburgh: NHS Health Scotland.

Institute for Health and Care Excellence's (2007) (NICE)<sup>19</sup> recommendations for the measurement of behaviour change. Specifically:

*The measurement of behaviour/s in a research design needs to hone the beliefs (both positive and limiting), capacities, motivations, other's attitudes [health and care professional's] as well as beneficiaries [such as those with LTCs and carers] perceived benefits, competitive factors (caring duties, access, value etc.), barriers and other conditions that drive self-management behaviours.*

See separate LiU Desk Research report outlining the findings of the desk exercise appended to this evaluation report in Appendix B.

### **2.6.3 Primary research methods**

A number of primary research methods were used to evaluate LiU in terms of behaviour change, impact, accessibility and SROI. These are now described in brief.

#### *Primary research methods conducted*

To understand the outcomes and impact (if any) LiU contributes to self-care and self-management when managing a LTC or caring duties, the cohort study involved five elements of primary research:

- Deliberative event with practitioners from care and health partners who were involved with the development of LiU to co-design an online practitioner change survey. See Appendix B for the findings report (n=1);
- 1 x week diaries to collect data via journal/diary entry (up to 8 x 1-week diaries completed over a 2-month period per respondent) (n=217);
- Sixty-minute telephone depth interviews across the control and intervention samples (n=19);
- Vignette / case studies of active users typifying main impact findings (n=7); and.
- An online practitioner survey (NB. Findings will be provided as an addendum to this report in June 2016. Survey completion numbers will be determined at that time).

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<sup>19</sup> NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE), 2007. *Behaviour change: general approaches*. London: NICE.

### *Self-completion diary method*

The key type of primary research undertaken within the evaluation was the conduct of social research within a self-completion diary finished by the intervention and control groups.

Diaries allowed an ethnographic research approach<sup>20</sup> or a 'day in the life of' data to be collected daily over a 2-month period of the study. Questions in the diary were based on a Theory of Change using a combination of Azjen's Theory of Planned Behaviour<sup>21</sup> and the Patient Activation Model (PAM model)<sup>22</sup>.

### *Azjen's Theory of Planned Behaviour*

Azjen's theory of change was used to inform the diary design because a systematic review of its application to health related behaviours evidenced that this theory performed well in explaining behavioural 'intention'. The Review also noted that attitude and perceived behavioural control over actions undertaken were critical to predicted behaviour<sup>23</sup>.

### *Patient Activation Model (PAM Model)*

The 'Patient Activation Model' (PAM) was also used within the diary design because Patient Activation Measures (PAM) are patient-reported measures that have been extremely well validated in the United Kingdom<sup>24</sup>.

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<sup>20</sup> According to the Government Service Design Manual, ethnographic research usually involves observing target users in their natural, real-world setting, rather than in the artificial environment of a lab or focus group. The aim is to gather insight into how people live; what they do; how they use things; or what they need in their everyday or professional lives. THE UK GOVERNMENT, 2014. *Ethnographic research: getting input into products and services*. [online]. London: The UK Government. [Available from: <https://www.gov.uk/service-manual/user-centred-design/user-research/ethnographic-research.html>] [Accessed February 2016].

<sup>21</sup> GODIN, G. and KOK, G., 1996. The Theory of Planned Behaviour: A review of its application to health related behavior. *The American Journal of Health*, 11(2), PP. 87-98.

<sup>22</sup> HIBBARD, J. and GILBERT, H., 2014. *Supporting people to manage their health: An introduction to patient activation*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf) [Accessed March 2016].

<sup>23</sup> GODIN, G. and KOK, G., 1996. The Theory of Planned Behaviour: A review of its application to health related behavior. *The American Journal of Health*, 11(2), PP. 87-98.

<sup>24</sup> HIBBARD, J. and GILBERT, H., 2014. *Supporting people to manage their health: An introduction to patient activation*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf) [Accessed March 2016].

PAM scores (at a level of significance or mean) are validated to be a powerful and reliable measure and have been robustly demonstrated to predict a number of health behaviours<sup>25</sup>. PAM scores have also been used across a wide range of studies involving the detection of self-management in people with long-term conditions<sup>26</sup>.

### *What PAM scores mean*

Participants with higher PAM scores are more likely to adopt healthy behaviours, to have better clinical outcomes and lower rates of hospitalisation and, to report higher levels of satisfaction with services<sup>27</sup>.

Consequently, patients with low activation levels are more likely to attend accident and emergency departments, to be hospitalised or to be re-admitted to hospital after being discharged. This is likely to lead to higher health and care costs<sup>28</sup>.

It therefore follows that participants in this evaluation study who had lower PAM scores are evidenced to be less likely to play an active role in staying healthy and managing their LTC<sup>29</sup>. They are less good at seeking help when they need it, at following a doctor's advice and at managing their health when they are no longer being treated<sup>30</sup>. Their lack of

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<sup>25</sup> HIBBARD, J. and GILBERT, H., 2014. *Supporting people to manage their health: An introduction to patient activation*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf) [Accessed March 2016].

<sup>26</sup> HIBBARD, J. and GILBERT, H., 2014. *Supporting people to manage their health: An introduction to patient activation*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf) [Accessed March 2016].

<sup>27</sup> HIBBARD, J. and GILBERT, H., 2014. *Supporting people to manage their health: An introduction to patient activation*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf) [Accessed March 2016].

<sup>28</sup> HIBBARD, J. and GILBERT, H., 2014. *Supporting people to manage their health: An introduction to patient activation*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf) [Accessed March 2016].

<sup>29</sup> HIBBARD, J. and GILBERT, H., 2014. *Supporting people to manage their health: An introduction to patient activation*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf) [Accessed March 2016].

<sup>30</sup> HIBBARD, J. and GILBERT, H., 2014. *Supporting people to manage their health: An introduction to patient activation*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf) [Accessed March 2016].

confidence and their experience of failing to manage their health often means that they prefer not to think about it<sup>31</sup>.

Clearly, when used to inform the design of the cohort study for LiU, the PAM model is a useful tool for comparing scores for active users and non-users of LiU where their management of their LTC is concerned.

### *Telephone interviews*

Telephone interviews were used to interrogate the self-reported data diaries and to provide further insights.

In particular, telephone interviews were used to explore both positive and challenging experiences that each respondent had encountered during the diary research period. This enabled the study team to explore any significant findings regarding their social resilience, sense of care routines and to explore other findings regarding their individual PAM scores<sup>32</sup> and intentions, actions and feelings.

Telephone interviews were also used to rate the importance of LiU to each 'active user' in terms of health and wellbeing using a simple Likert scale<sup>33</sup>, supporting attribution of LiU to the findings. The scale used was selected by respondents using a score of 1-5 where five was exceptional importance and 1 was of little or no importance.

### *Vignettes/case studies of active users of Living it Up*

Vignettes are in-depth case studies that illustrate respondent information in a personalised way to aid greater understanding. Vignettes are used in the Impact Chapter of this report. Each vignette summarises the social, familial, health and well-being contexts of participants in the study.

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<sup>31</sup> HIBBARD, J. and GILBERT, H., 2014. *Supporting people to manage their health: An introduction to patient activation*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf) [Accessed March 2016].

<sup>32</sup> HIBBARD, J. and GILBERT, H., 2014. *Supporting people to manage their health: An introduction to patient activation*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf) [Accessed March 2016].

<sup>33</sup> SOCIAL RESEARCH METHODS, 2006. *Likert Scaling*. [online]. Social Research Methods Available from: <http://www.socialresearchmethods.net/kb/scallik.php> [Accessed [15 February 2016].

## Online practitioner survey

Readers are invited to note that the findings from the online practitioner survey are not presented in this report as they are not yet available.

## 2.7 Determining significance for behaviour change and impact

There were two steps used to analyse the significance of scores self-reported by participants in the diary data.

The Patient Activation Model (PAM)<sup>34</sup> data section was first analysed by the calculation of the mean for each group. No significance in the findings were detected when using a Chi-Squared Test. However, since PAM scores are a reliable measure and have been robustly demonstrated to predict a number of health behaviours<sup>35</sup>, it was deemed appropriate by the study team to draw attention to any differences by using mean scores between the intervention and control groups.

For the remainder of the diary questions, the mean was calculated and a Chi-Squared test performed to test for difference between the Intervention and Control group. This was conducted for each question/statement, due to the non-parametric nature of the data, again to test for statistical significance<sup>36</sup>. As with all other similar studies significance was set at  $p \leq 0.05$ <sup>37</sup>.

An independent review of all of the statistics by a statistician has been undertaken to verify the findings.

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<sup>34</sup> HIBBARD, J. and GILBERT, H., 2014. *Supporting people to manage their health: An introduction to patient activation*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf) [Accessed March 2016].

<sup>35</sup> HIBBARD, J. and GILBERT, H., 2014. *Supporting people to manage their health: An introduction to patient activation*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/supporting-people-manage-health-patient-activation-may14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf)

<sup>36</sup> COHEN. L., MANION. L. and MORRISON, K., 2000. *Research Methods in Education*. 5<sup>th</sup> ed. London: RoutledgeFalmer.

<sup>37</sup> DO, V. et al., 2015. Relationships between activation level, knowledge, self-efficacy, and self-management behaviour in heart failure patients discharged from rural hospitals. *F1000Research*, 4(150), pp. 1-11.

## 2.8 Method used to determine the accessibility of Living it Up (as at 31.1.16)

The approach used to gauge the accessibility of LiU to those with long-term conditions and/or carers is based upon the guiding principles of The Government's Service Design Manual specific to Web Content Accessibility Guidelines WCAG AA level standard and WC3 standards (2013)<sup>38</sup>. Readers are invited to note however, that accessibility of LiU falls out-with a theory of change analysis because it is guided by accepted governmental standards that guide digital accessibility such as the Level AA of the Web Content Accessibility Guidelines (WCAG) 2.0 and W3C that is a collection of Accessibility Evaluation Resources<sup>39</sup>. See Accessibility in Section Five of this report for detailed analysis.

WCAG 2.0 is a technical standard that public services online need to meet, and not an introduction to accessibility. It has 12 guidelines that are organised under 4 principles:

1. Perceivable;
2. Operable;
3. Understandable; and,
4. Robust.

For each guideline, there are testable success criteria, which are at three levels: A, AA, and AAA.

### 2.8.1 Accessibility standards to assess Living it Up

Web Content Accessibility Guidelines (WCAG) is developed through the W3C process in co-operation with individuals and organisations around the world. The purpose of the standard is to set a single shared standard for web content accessibility that meets the needs of individuals, organisations, and governments internationally<sup>40</sup>.

To assess the accessibility of LiU a number of methods have been used.

- A review of website visitors statistics using independent online tools;
- Comparisons with similar websites; and,

<sup>38</sup> THE UK GOVERNMENT, 2014. *Accessibility. How to make services that everyone can use*. [online]. London: The UK Government. Available from: <https://www.gov.uk/service-manual/user-centred-design/accessibility> [Accessed February 2016].

<sup>39</sup> THE UK GOVERNMENT, 2014. *Accessibility. How to make services that everyone can use*. [online]. London: The UK Government. Available from: <https://www.gov.uk/service-manual/user-centred-design/accessibility> [Accessed February 2016].

<sup>40</sup> THE UK GOVERNMENT, 2014. *Accessibility. How to make services that everyone can use*. [online]. London: The UK Government. Available from: <https://www.gov.uk/service-manual/user-centred-design/accessibility> [Accessed February 2016].

- Communication with the LiU web team and a review of the goals and targets published by the LiU website project.

The website visitor reports were drawn from Google Analytics and LiU website performance reports. The review period was from January 2015 to January 2016 (some statistics were not available for the entire period due to the re-development of LiU taking place from February 2016).

## 2.9 Method used to calculate a Social Return on Investment (SROI) for Living it Up

SROI is a principles-based approach to measuring social value for a range of stakeholders involved in any one project or programme. SROI can best be described as an accounting approach applied to social issues borrowing in places from economics, CBA and sustainability reporting. Some of its principles and methods are shared with 'Social Cost Benefit Analysis', the Treasury Green Book preferred method of project appraisal which seeks to express the full social costs and full social benefits of policies in monetary terms so that the consequences of a diverse range of policies can be compared using a common metric. The full social costs and benefits extend beyond the financial consequences of the policy and The Green Book contains guidance that wider social and environmental impacts must be brought into the assessment as far as possible, through using valuation techniques for non-market goods.<sup>41</sup>

Within the context of this evaluation, a SROI approach has been used to explore the potential economic and social benefit that LiU provides in health and care, through analysing the social return on investment for LiU.

The 7 principles of SROI that have been applied to calculating the value of the outcomes for the 17 people with LTCs and/or carers in the intervention group are:

- Involve stakeholders/parties involved in the project;
- Understand outcomes from the perspective of all or key stakeholders/parties;
- Value what matters;
- Only include what is material;
- Avoid 'over-claiming' value;

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<sup>41</sup> See for example 'Valuation techniques for Social Cost Benefit Analysis' 2011, Fujiwara and Campbell, HM Treasury and DWP at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/209107/greenbook\\_valuationtechniques.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/209107/greenbook_valuationtechniques.pdf)

- Be transparent; and,
- Verify the story/account.

Readers should note that it has not been possible to apply SROI principles to the whole value of LiU at this stage because the primary research focused on beneficiary outcomes (as was the request of the tender) rather than on practice, policy and process change.

### **2.9.1 Stakeholder outcomes that are included in Living it Up's SROI calculation**

Stakeholders that have taken part in the research process, for whom data has been collected and, outcomes have been verified are included in the Impact Map in Appendix F. Outcomes arising from the active use of LiU have been valued in terms of LiU's importance to supporting self-care and self-management of those with LTCs.

Stakeholders that are included in the SROI are:

- LiU 'active users' i.e. people living with long-term health conditions for more than 12 months who are registered for the monthly newsletter, use digital tools and/or possibly contribute content to LiU and who use LiU more than twice per month; and,
- Carers of people with long-term health conditions, who also have long-term conditions themselves.

There are also stakeholders which have been identified as material, inferred from the primary research reports from LiU users and carers in this study. Where the primary data is directly collected from active users, this has been used to infer an impact and has been factored into calculations with two other stakeholder groups. These are:

- Community-based organisations who benefit from LIU active user's engaging in volunteering activity
- NHS primary care services.

The NHS services are intended beneficiaries of LIU, inferred from the research with LIU active users, whereas community-based organisations are unintended beneficiaries but are positively impacted on by LIU.

Participants that opted-in to the research reported no involvement with any of LiU's larger self-management initiatives such as 'GetActive' and SmartCare. In the likely event that respondents had been involved in these larger initiatives, the SROI process could have taken that into account.

### **2.9.2 Stakeholder outcomes not included in Living it Up's SROI calculation**

There are significant stakeholders who may experience a material impact and lasting legacy as a result of being involved in LiU, but for whom there is no primary research evidence to be able to include them in the impact map at this stage. These are:

- Members of LiU who are actively involved in self-management services that are supported via LiU (because those users of LiU that self-elected into the evaluation all reported that they were not involved in LiU services like Get Active);
- Members of LiU that receive a monthly newsletter but do not report using LiU more than twice per month, the impact for whom is currently not recorded online or by another means; and,
- Local health and social care practitioners working within the local partnership areas, whose practice survey results are being collected in a different phase of research and, so could not be included in the impact map and the SROI calculation at this stage.

These are also potential stakeholder groups for whom the study team has insufficient evidence to make a judgment as to whether a material impact or not has occurred, as these have affected the SROI calculation. See Chapter 4: Social Return On Investment.

For example, such stakeholders might be 'casual users' of LiU who browse LiU but do not register as a full member and professional care, community and health practitioners who may use LiU.

### **2.9.3 Study design limitations**

There are a number of limits to the evaluation study for LiU. These are common to most/all social research studies.

Social research projects vary widely and research involving human populations is intrinsically difficult according to the Social Research Association<sup>42</sup> due to the following:

- People are highly complex and language is imprecise;
- Human beliefs, values, attitudes and motivations are hard to identify precisely;
- Memory is fallible and research respondents are not always able or willing to report their feelings or behaviour accurately or honestly; and,
- There can be statistical problems in drawing valid inferences about large and shifting human populations.

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<sup>42</sup> Social Research Association 'Commissioning Good Social Research Practice Guide' (2012) Available at: (<http://the-sra.org.uk/wp-content/uploads/Commissioning-Social-Research-good-practice-guide-2nd-ed.pdf>)

The above factors therefore limit the methods used within LiU's cohort study.

Social research therefore cannot normally be reduced to a mechanical formula (like a randomised control trial can be) and good research needs to craft research tools using experienced skills and intelligent creativity in the way they are applied as well as an ability to understand the way people think, feel and behave. Within any social research method that is selected, there are limits to the study because of the methods selected and samples collected<sup>43</sup>.

The cohort study was also limited by the scope and the objectives set for the three evaluations conducted. Plus, it was limited by the small sample size that was independently recruited due to the budget available.

In addition, it was limited in terms of interpretation of impact by using a theory of change method to design the research tools as well as to analyse data collected.

Other limiting factors such as a strong regional focus i.e. only examining five health board areas and focusing on areas of self-management and self-care for those with long-term conditions and carers aged over 50 was limiting.

A final type of limitation is that of statistical or data limitations. Statistical limitations can also stem from study design, producing more serious limitations in terms of interpreting the findings. In this study, over 25,000 points of data were collated over a two month period so this presented a small, but evident statistical limitation.

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<sup>43</sup> Social Research Association 'Commissioning Good Social Research Practice Guide' (2012) Available at: (<http://the-sra.org.uk/wp-content/uploads/Commissioning-Social-Research-good-practice-guide-2nd-ed.pdf>)

## 3.0 BEHAVIOUR CHANGE FINDINGS

### 3.1 How this chapter is structured

This chapter details the extent of behaviour change that has been found to be statistically significant in the cohort study for the intervention group.

This chapter details significant findings for those aged 50 and over who are managing a long-term condition and/or carers in terms of behaviour change. This chapter also includes the mean score findings using PAM scores.

#### 3.1.1 Table of significant findings for those aged 50 and over with long-term conditions and/or carers

There are six statistically significant findings contributing to behaviour change that can be attributed to those aged over 50 with a long-term condition and/or carers who are active users of LiU. These are listed in table 1.0.

The Patient Activation Model (PAM) findings (see Appendix D for a full list of graphs and tables) was analysed by the calculation of the mean for each sample group. Patient Activation Model Scores (PAM Scores) were tested for significance and were found not to have any significance.

PAM scores are a reliable measure and have been robustly demonstrated to predict a number of health behaviours. Accordingly, due to the robustness of the PAM model and the volume of data collected it was deemed appropriate to use mean scores by the study team to draw attention to any differences in mean PAM scores between the intervention and control group.

These are listed in table 1.0 next.

#### 3.1.2 Table 1.0 Statistically significant findings for behaviour change that can be attributed to active users of Living it Up in the cohort study

No.	Graph No.	Description	P value	Intervention /Control group
	-	Data collected in diary research using theory of change	Significance Level $\leq 0.05^*$	Mean

a	2.1	Intervention group reported increased levels of volunteering and social and community connectedness	0.03	1.88/ 9.25
b	3.1	Intervention group reported "going online/viewed a website including non-prompted responses mentioning Living it Up" to make themselves feel better than the control group	0.01	12.39/ 1.85
c	3.2	Intervention group participants with LTCs contacted care professionals far less than the control group	0.05	0.62/ 1.69
d	2.2. & 2.3	Increased capacity to care for others exhibited by intervention group	0.004 & 0.04	1.5/ 14.13 & 1.88/ 3.38
e	3.5	Greater extent of trial of new caring and LTC techniques for self-management	0.03	5.33/ 1
f	3.3	Lower instance in intervention of LTC's contacting community/volunteering services	0.04	1.23/ 2.46
<b>Patient activation model mean scores</b> (greater than 0.4 difference)				
-	-		Intervention Mean score	Control Mean score
g	4.4	Carers in the intervention group believe that taking an active role in their own health care is the most important factor in determining their health and well-being compared to those in the control group	4.3	3.85
h	4.2	Carers in the intervention group believe to a greater degree that they should be responsible for managing their health and well-being more so than those in the control group.	4.72	3.98
i	4.5 & 4.6	Participants with LTC's and carers in the intervention group are more confident that they can take action to prevent symptoms and problems associated with their health condition to a greater degree than those in the control group	4.24 & 4.34	3.86 & 3.83
j	4.8	Carers in the intervention group reported a higher score for the statement that they know what each of their prescribed medications does for the person they care for than the control group	3.57	2.5
k	4.18	Carers in the intervention group recorded a higher score than the control group for the statement "I understand the nature and causes of my own health condition(s)"	3.04	2.52

\* DO, V. et al., 2015. Relationships between activation level, knowledge, self-efficacy, and self-management behaviour in heart failure patients discharged from rural hospitals. *F1000Research*, 4 (150), pp. 1-11

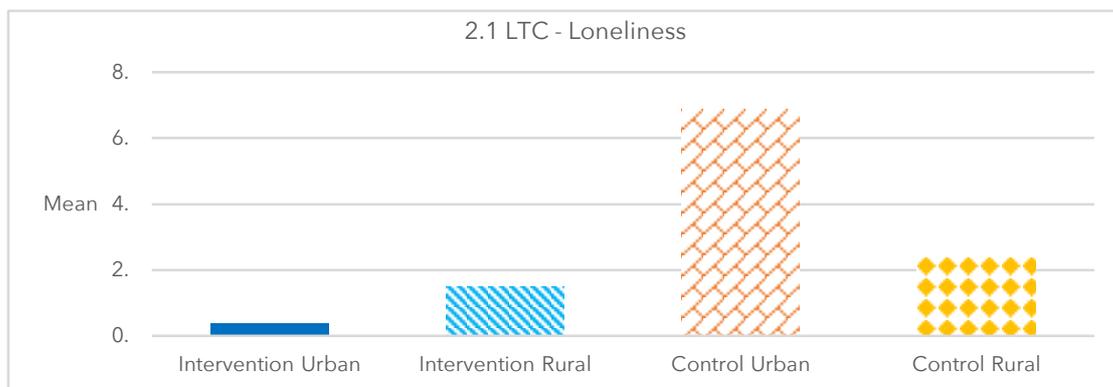
The importance of findings a) to k) to behaviour change and capacity to self-care and/or self-manage a long-term conditions found within the cohort study are discussed in more detail next.

### 3.1.3 a) Increased levels of volunteering and social and community connectedness

This finding is evidenced by the mean score for loneliness in intervention group being significantly lower than that reported in the control group in figure A below.

Increased levels of social and/or community connectedness is important to behaviour change because evidence from the report Predicting Depression and Self-Esteem from Social Connectedness, Support and Competence (2006)<sup>44</sup> shows that social functioning has long-term benefits. Specifically, access to social support and social skill or competence correlates to greater well-being and psychological functioning<sup>45</sup>. Figure A below shows the mean score (6.8) for the reported level of loneliness by the control group (16). In contrast, the mean score for loneliness reported by the intervention group is 1.9.

Figure A. Graph to show the mean score for loneliness reported by intervention and control groups broken into urban and rural study respondents



<sup>44</sup> WILLIAMS, K.L. and GALLIHER, R.V., 2006. Predicting Depression and Self-Esteem from Social Connectedness, Support and Competence. *Journal of Social and Clinical Psychology*, 25(8), pp. 855-874.

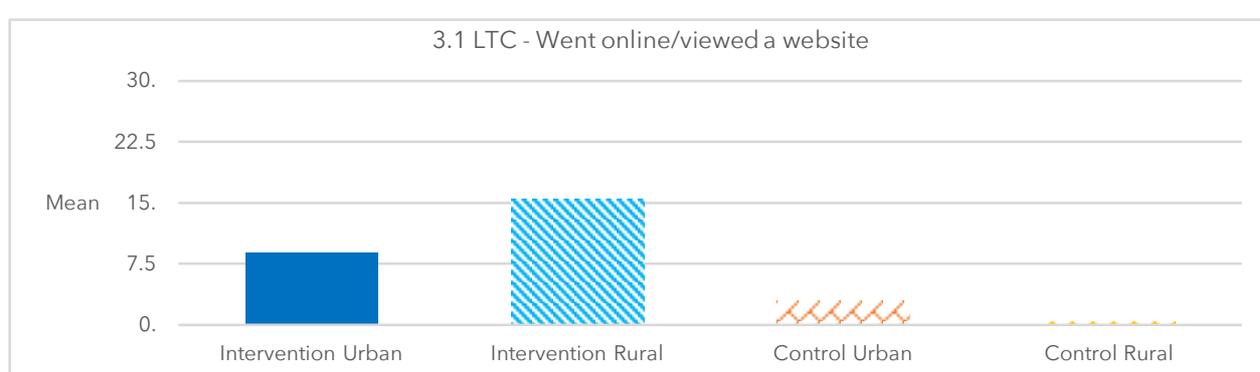
<sup>45</sup> WILLIAMS, K.L. and GALLIHER, R.V., 2006. Predicting Depression and Self-Esteem from Social Connectedness, Support and Competence. *Journal of Social and Clinical Psychology*, 25(8), pp. 855-874.

### 3.1.4 b) Proactive search for information to do with managing their long-term health condition

Compared with the control group, the intervention group were significantly more likely to report “going online/viewed a website [including LiU]” to make themselves feel better.

This finding is evidenced by the significant scores (15) for rural respondents in the intervention group (18) being higher than the control group (16) score (3) during the same period. This is illustrated in figure B below.

Figure B. Graph to show the mean scores for ‘Going online and viewing a website including Living it Up’ by intervention group and control group respondents over 2-month period



*The importance of proactive search for the management of long-term conditions and self-care*

The proactive search for information for managing a long-term health condition was identified to be important in generating behaviour change by The Kings Fund Report: Delivering better services for people with long-term conditions: Building the house of care (2013)<sup>46</sup>.

This report states that ‘a growing body of evidence underscores the importance of effective self-management of long-term conditions (Epping-Jordan et al. 2004)<sup>47</sup> and argues that people who are more ‘activated’ (that is, who recognise that they have an important role in

<sup>46</sup> COULTER, A., ROBERTS, S. and DIXON, A., 2013. *Delivering better services for people with long-term conditions: Building the house of care*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/delivering-better-services-for-people-with-long-term-conditions.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/delivering-better-services-for-people-with-long-term-conditions.pdf) [Accessed February 2016]. p. 3.

<sup>47</sup> EPPING-JORDAN, J.E., et al., 2004. Improving the quality of health care for chronic conditions. *Quality and Safety in Health Care*, 13(4), pp. 299-305.

self-managing their condition and have the skills and confidence to do so) experience better health outcomes' (Greene and Hibbard 2012)<sup>48</sup>.

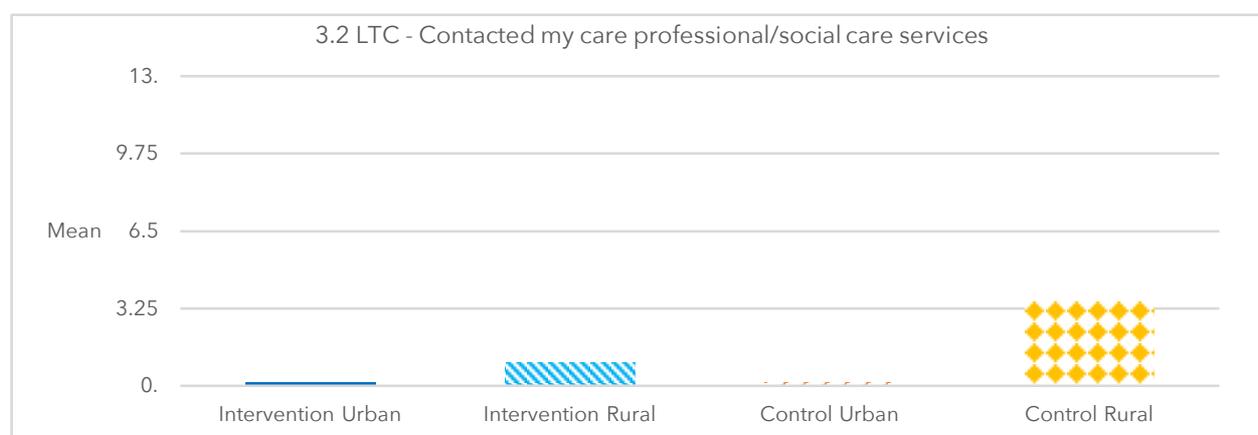
The report also states 'that with effective support, information and education, evidence shows that preventative health and care skills can be developed and strengthened, even among those who are initially less confident, less motivated or have low levels of health literacy' (Hibbard and Greene 2013)<sup>49</sup>.

### 3.1.5 c) Lower instance of contacting care services for those using Living it Up

Active users of LiU within the intervention group significantly reported a three times lower instance of attending care services over the study period than the control group.

This finding is evidenced by the mean scores for respondents in the intervention group being significantly lower (<1) than the control group's mean score (3.25) during the same period. Mean scores for reported attendance with health and care services are illustrated in figure C.

Figure C. Graph to show the mean scores of those with LTCs contacting health and care services during



This finding is important to both behaviour change and public spending on integrated care supporting those with long-term conditions in Scotland.

<sup>48</sup> GREENE, J and HIBBARD, J. H., 2012. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine*, 27(5), pp. 520-526.

<sup>49</sup> HIBBARD, J.H. and GREENE, J., 2013. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Affairs (Millwood)*, 32(2), pp. 207-214.

For behaviour change, a lower instance of attending care services by active users of Living it Up in the intervention group is significant because it evidences a higher level of patient activation (Greene and Hibbard 2012)<sup>50</sup> leading to better health outcomes for those using Living it Up 2+ or more per month.

For public expenditure, this is also a significant finding as rates of LTCs experienced by people living in Scotland are set to increase and people of working age by 2031 is set to reduce by 7% providing a constriction in available public expenditure<sup>51</sup>.

### **3.1.6 d) Increased capacity to care for others exhibited by active users of Living it Up**

Carers in the control group significantly reported feeling low over the research period and cited their caring duties as the main reason for this.

This finding is important because it suggests that the resilience of carers in the control group is far lower than the resilience levels of active users of LiU in the intervention group (figure D mean: 1.5/ 14.13 respectively & figure D.1 mean: 1.88/ 3.38 respectively).

Resilience is the ability to cope with pressure and underpins safe, high-quality, person-centered care and support<sup>52</sup>.

Developing the resilience of carers is one of the key planks of meeting the integrated health and care 2020 Vision for NHSScotland and 'enabling care at home or in a homely setting'<sup>53</sup>.

Resilience is an essential skill for all who work in adult social care and behaviours associated with resilience in caring roles include<sup>54</sup>:

1. Understanding and valuing the meaning of what you do at work;
2. Doing what you can to get on with the people around you;

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<sup>50</sup> GREENE, J and HIBBARD, J. H., 2012. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine*, 27(5), pp. 520-526.

<sup>51</sup> AUDIT SCOTLAND, 2007. *Managing long-term conditions*. [online]. Edinburgh: Audit Scotland. Available from: [http://www.audit-scotland.gov.uk/docs/health/2007/nr\\_070816\\_managing\\_long\\_term.pdf](http://www.audit-scotland.gov.uk/docs/health/2007/nr_070816_managing_long_term.pdf) [Accessed February 2016].

<sup>52</sup> BRADDELL, A., 2015. *Understanding resilience: What is it? Why does it matter?* [online]. Leeds: Skills for Care. Available from: <http://www.skillsforcare.org.uk/Documents/Topics/Mental-health/Resilience-Section-1-What-is-resilience.pdf> [Accessed February 2016].

<sup>53</sup> AUDIT SCOTLAND, 2007. *Managing long-term conditions*. [online]. Edinburgh: Audit Scotland. Available from: [http://www.audit-scotland.gov.uk/docs/health/2007/nr\\_070816\\_managing\\_long\\_term.pdf](http://www.audit-scotland.gov.uk/docs/health/2007/nr_070816_managing_long_term.pdf) [Accessed February 2016].

<sup>54</sup> BRADDELL, A., 2015. *Understanding resilience: What is it? Why does it matter?* [online]. Leeds: Skills for Care. Available from: <http://www.skillsforcare.org.uk/Documents/Topics/Mental-health/Resilience-Section-1-What-is-resilience.pdf> [Accessed February 2016].

3. Taking a problem-solving approach to difficulty;
4. Keeping a sense of perspective (and humour) when things go wrong;
5. Being flexible and willing to adapt to change and to learn;
6. Greeting new situations, new people, new demands with a positive attitude;
7. Drawing on a range of strategies to help you cope with pressure and change; and,
8. Recognising your thoughts and emotions and managing them.

This finding is evidenced by the mean scores for respondents in the intervention group (n=18) being significantly lower (1) than the control group's mean score (8.5) during the same period when citing caring duties as pressure for low mood.

Figure D and D.1 shows significantly higher levels of low mood cited by carers.

Figure D. Mean scores of carers citing time pressures for low mood during cohort study period

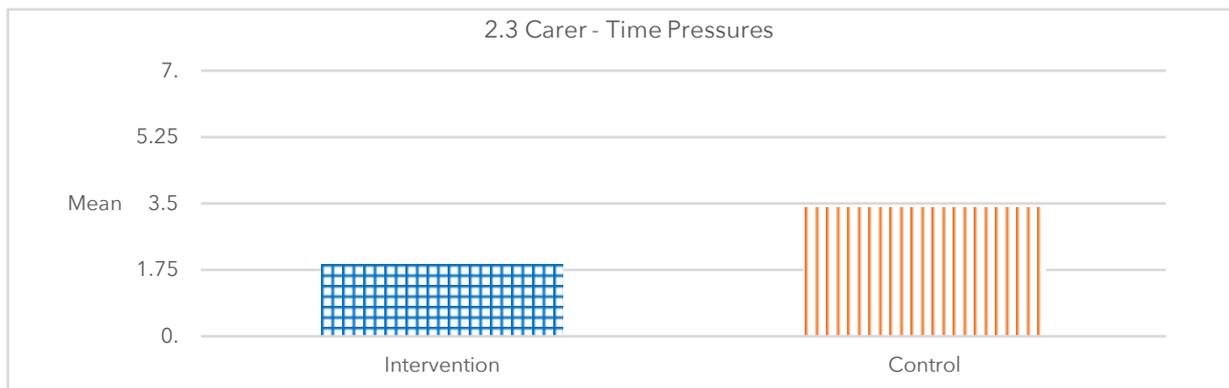
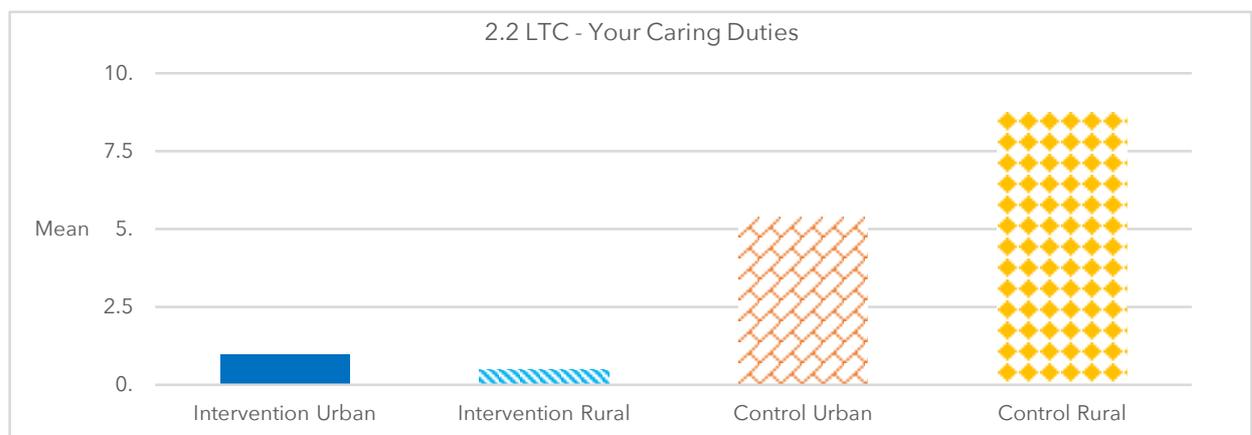


Figure D.1. Graph to show the mean scores of carers citing caring duties for low mood during cohort study



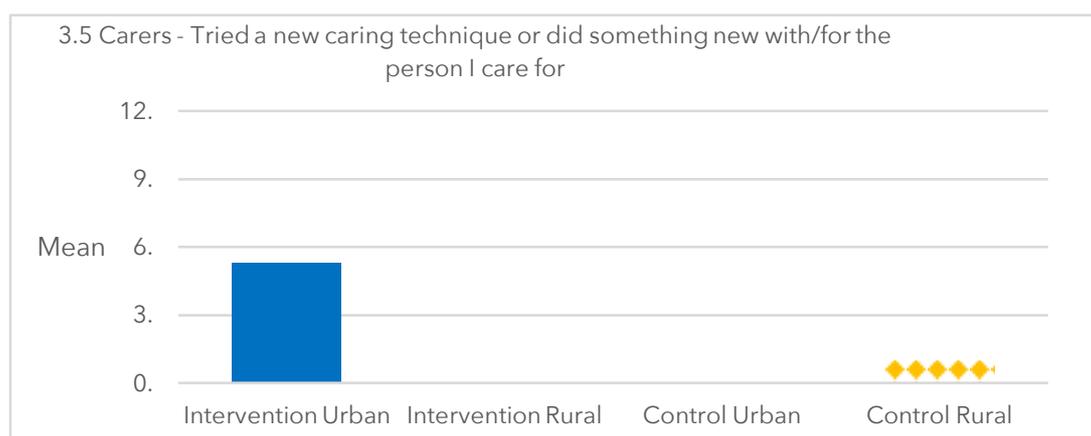
### 3.1.7 e) Carers who are active users of Living it Up tried new caring technique/s or did something new to manage a Long-term condition

Carers who are active users of LiU reported a significantly higher instance of attempting new caring techniques or something different to care or manage their own long-term condition when compared to carers in the control group.

This finding is evidenced by the mean scores for respondents in the intervention group being five times more likely (5) than the control group's mean score (1) during the same period. Mean scores for reported attendance with health and care services are illustrated in figure E below.

This finding speaks to carers in the intervention group having both higher levels of resilience to care and a lower instance of attending care services as a result of higher levels of activation (Greene and Hibbard 2012)<sup>55</sup>. This in turn leads to better health outcomes for those they care for and for their own caring duties when using LiU >2 times per month.

Figure E. Mean scores for intervention group and control group trying a new caring technique



### 3.1.8 f) Lower instance of active users contacting community/volunteering services

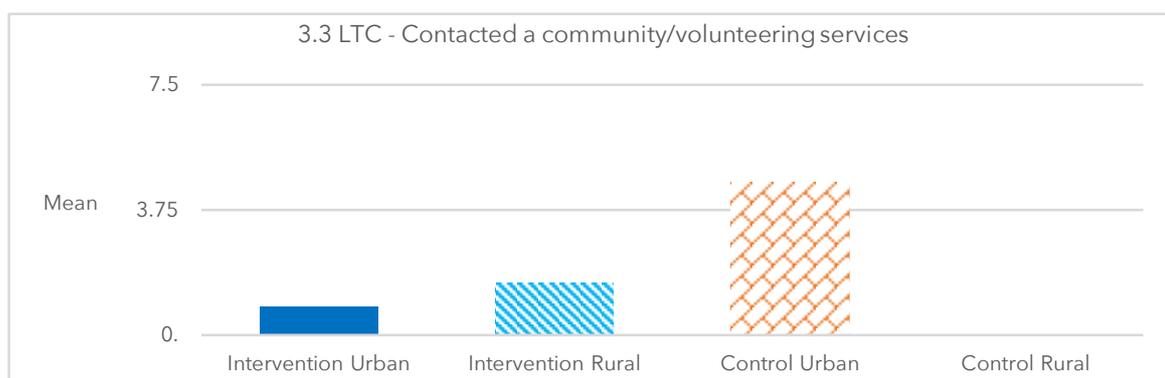
Those with LTCs who are active users of Living it Up within the intervention group significantly reported a lower instance of contacting community/volunteering services over the study period than the control group. However, they are more likely to volunteer in them.

This finding is evidenced by the mean scores for respondents in the intervention group being three times lower (>1) than the control group's mean score (>3.75) during the same period. Mean scores for reported attendance with health and care services are illustrated in figure F below.

<sup>55</sup> GREENE, J and HIBBARD, J. H., 2012. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine*, 27(5), pp. 520-526.

This finding is important to behaviour change and lowers the reliance upon the third sector of supporting those with long-term conditions in Scotland. For behaviour change, a lower instance of contacting community/volunteering services by active users of LiU in the intervention group is significant because it evidences a higher level of patient activation (Greene and Hibbard 2012)<sup>56</sup> leading to better health outcomes for those using LiU >2 times per month.

Figure F. Mean scores for LTC's contacting community/volunteering services in intervention and control groups



### Patient activation score findings

Higher mean score findings using Greene and Hibbard's (2013) Patient Activation statements (see method section for full explanation) were also found in the following areas of self-management of LTC. These are now described in more detail below.

#### 3.1.9 h) Greater personal responsibility taken by active users of Living it Up when managing long-term condition/s

Active users of Living it Up who also have caring roles (n=4) reported a higher instance of taking greater responsibility for managing their health and well-being when compared to carers in the control group (n=3).

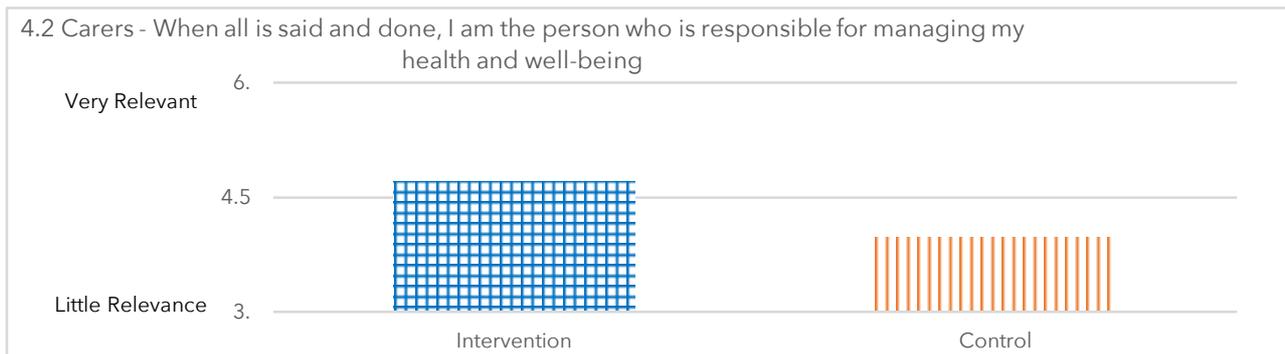
This is important because it suggests evidence that active users of LiU have increased levels of social resilience to care and support self-care. Readers are invited to note the small sample of carers in the sample when reading these.

<sup>56</sup> GREENE, J and HIBBARD, J. H., 2012. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine*, 27(5), pp. 520-526.

This finding is evidenced by the mean scores for respondents in the intervention group having a greater activation score (4.6) than the control group (3.6) in Figure H below.

Figure H. Shows a higher patient activation score for carers in the intervention group to take greater responsibility for their own health.

Figure H. Graph to show the PAM mean scores for the intervention group and control group for the statement 'When all is said and done, I am the person responsible for managing my health and well-being'



### 1. i) Those with a LTC report a more active role for preventing and minimising problems associated with their health condition

Active users of LiU reported a statistically significantly higher instance of taking a more active role for managing their health and/or doing something different to care or manage their own long-term condition when compared to those in the control group.

This finding is evidenced by the mean scores for respondents in the intervention group having a greater activation score (4.3 and 4.3) than the control group (3.9 and 3.8) in figures I and J below. i.e. users and carers.

Figure I. Shows the patient activation score for the intervention and control group for confidence to take action to prevent symptoms or problems associated with their health condition

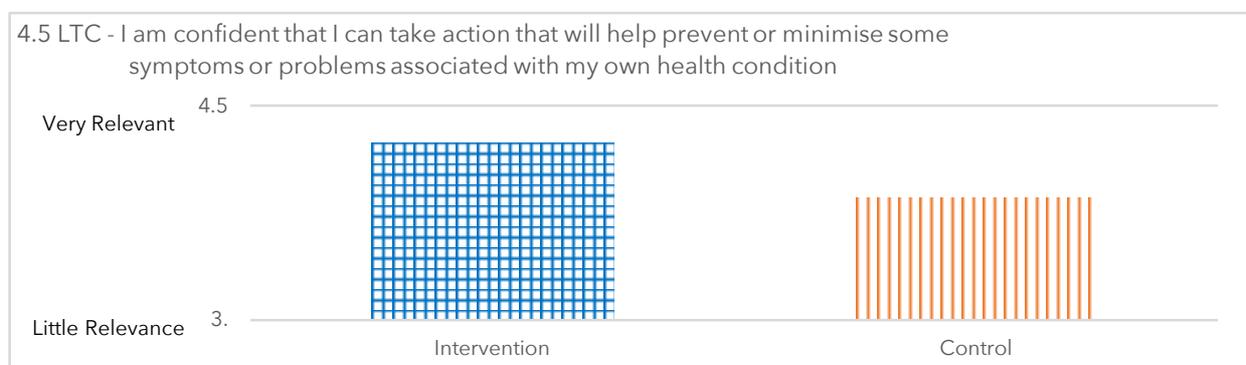
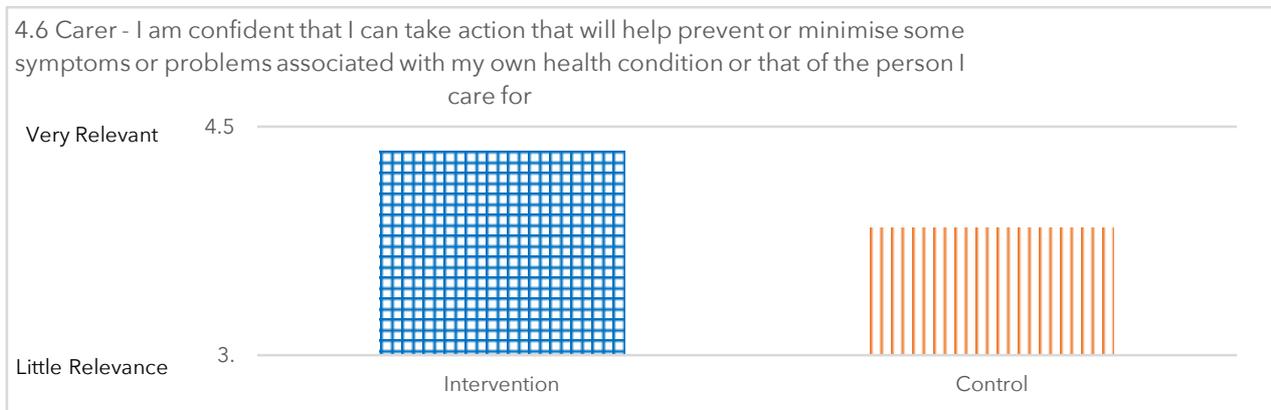


Figure J. Graph showing mean scores for carers in the intervention group helping to prevent or minimise some symptoms or problems associated health conditions



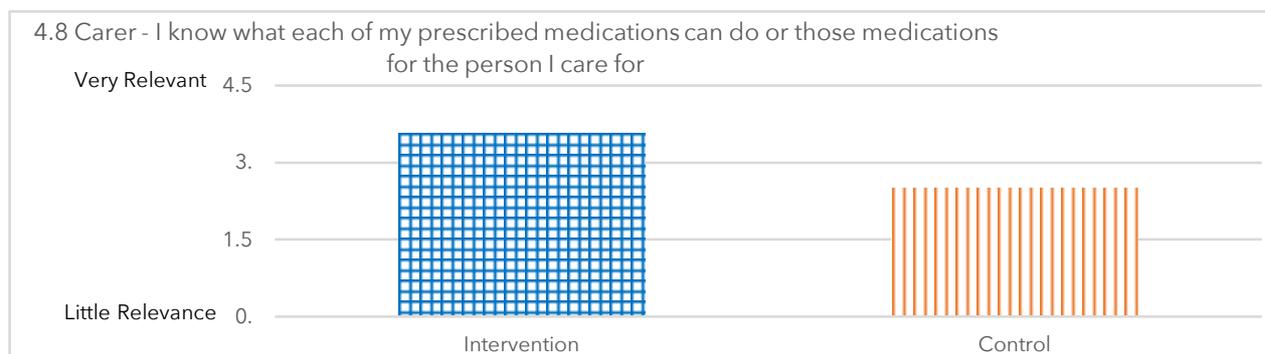
## 2. j) Active users of Living it Up with a LTC reported greater knowledge levels about medications

Active users of LiU (n=17) reported higher mean scores about their medications that they administer when managing their health condition than those in the control group (n=16).

This finding is important because it suggests evidence that active users of LiU have an understanding about the role they play in managing their health and how this impacts on their outcomes<sup>57</sup>.

Figure K. evidences the mean scores for respondents in the intervention group having a greater activation score (3.6) than the control group (2.5) below.

Figure K Table showing activation scores for knowledge about medications in the intervention and control groups



<sup>57</sup> FOOT, C. et al., 2014. *People in control of their own health and care: The state of involvement*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/people-in-control-of-their-own-health-and-care-the-state-of-involvement-november-2014.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/people-in-control-of-their-own-health-and-care-the-state-of-involvement-november-2014.pdf) [Accessed February 2016].

### 3. k) Active users in intervention group understand more about causes of own health condition

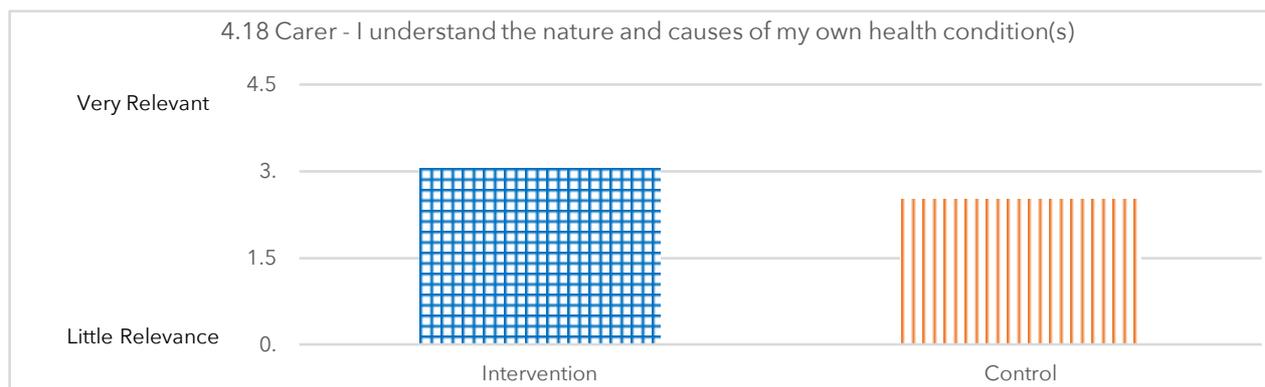
Active users of Living it Up who are carers reported statistically significantly higher levels of understanding about the causes of their health conditions when contrasted with those in the control group.

This finding is important because it suggests evidence that active users of LiU have an understanding about the role they play in managing their health and how this impacts on their outcomes<sup>58</sup>.

This understanding is important to managing changes to their long-term health conditions when conducting self-care and self-management of their long-term health condition.

This finding is evidenced by the mean scores for respondents in the intervention group having a greater activation score (3) than the control group (2.5) in Figure L. below.

Figure L. Understanding more about causes of own health condition within the intervention and control group



### 4. Significant findings in rural and urban locations

There are a small number of findings that are of interest and significant to participants in the study living in rural and urban locations. These are summarised in Table 1.3.

Readers are reminded to take into account that the significance of findings in the table, when broken down into rural and urban locations across the intervention and control groups, are based on small numbers of participants.

<sup>58</sup> FOOT, C. et al., 2014. *People in control of their own health and care: The state of involvement*. [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/people-in-control-of-their-own-health-and-care-the-state-of-involvement-november-2014.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/people-in-control-of-their-own-health-and-care-the-state-of-involvement-november-2014.pdf) [Accessed February 2016].

**5. Table 1.3 Significant findings from cohort study regarding urban and rural groupings**

Graph No. in Appendix	Description	Significance $\leq 0.05$ (Do et al. 2015)
3.4	Carers living in rural areas from the control group significantly reported "sourcing tips from books/leaflets" about their LTC more than intervention group carers from rural locations	0.01
2.1	Those with LTCs in the control group living in rural areas reported "loneliness" significantly as a reason behind their day to day 'feeling low mood'	0.03
3.5	Carers living in urban areas within the intervention group tried a new caring technique or did something new significantly more than the control group	0.03
3.3	Carers in urban locations in the control group contacted community/volunteering services significantly more than urban carers in the intervention group	0.04
3.2	Those with LTC's living in rural areas from the control group contacted their care professional/social care services more than those living in rural areas within the intervention group	0.05

## 4.0 IMPACT OF LIVING IT UP ON INDIVIDUAL OUTCOMES

This Chapter analyses the significant findings in 'Chapter two: Behaviour Change' to determine the impact of LiU.

The statistically significant findings from the intervention group have been collated analysed using a theory of change to suggest the impacts currently delivered by LiU to active users.

This chapter focuses on the self-management and self care routines in terms of the management of long-term conditions and uses graphs, tables and detailed case studies or vignettes to illustrate the specific areas of evidenced impact of LiU for active users.

### 4.1 Summary impact of Living it Up

Chapter three outlines six statistically significant findings that can be attributed to those aged over 50 with a long-term condition and/or carers who are active users of LiU. These are listed in table 1.0.

The Patient Activation Model (PAM) findings (see Appendix D for a full list of graphs and tables) was described by the calculation of the mean for each sample group. Patient Activation Model Scores (PAM Scores) were tested against the 12 PAM statements within the PAM model for significance. This analysis found no statistical significance.

PAM scores are a reliable measure and have been robustly demonstrated to predict a number of health behaviours<sup>59</sup>. Accordingly, due to the robustness of the model and the volume of data collated within that model, it was deemed appropriate by the study team to draw attention to any differences in mean PAM scores between the intervention and control group.

These are listed in table 1.0.

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<sup>59</sup> MICHIE, S., VAN STRALEN, M. M. and WEST, R., 2011. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6(42), pp. 1-11.

**4.1.1 Table 1.0 Statistically significant findings for behaviour change that can be attributed to active users of Living it Up in the cohort study**

No.	Graph No.	Description	P value	Intervention /Control group
	-	Data collected in diary research using theory of change	Significance Level $\leq 0.05^*$	Mean
a	2.1	Intervention group reported increased levels of volunteering and social and community connectedness	0.03	1.88/ 9.25
b	3.1	Intervention group reported "going online/viewed a website including non-prompted responses mentioning Living it Up" to make themselves feel better than the control group	0.01	12.39/ 1.85
c	3.2	Intervention group participants with LTCs contacted care professionals far less than the control group	0.05	0.62/ 1.69
d	2.2. & 2.3	Increased capacity to care for others exhibited by intervention group	0.004 & 0.04	1.5/ 14.13 & 1.88/ 3.38
e	3.5	Greater extent of trial of new caring and LTC techniques for self-management	0.03	5.33/ 1
f	3.3	Lower instance in intervention of LTC's contacting community/volunteering services	0.04	1.23/ 2.46
<b>Patient activation model mean scores</b> (greater than 0.4 difference)				
-	-		Intervention Mean score	Control Mean score
g	4.4	Carers in the intervention group believe that taking an active role in their own health care is the most important factor in determining their health and well-being compared to those in the control group	4.3	3.85
h	4.2	Carers in the intervention group believe to a greater degree that they should be responsible for managing their health and well-being more so than those in the control group.	4.72	3.98
i	4.5 & 4.6	Participants with LTC's and carers in the intervention group are more confident that they can take action to prevent symptoms and problems associated with their health condition to a greater degree than those in the control group	4.24 & 4.34	3.86 & 3.83
j	4.8	Carers in the intervention group reported a higher score for the statement that they know what each of their prescribed medications does for the person they care for than the control group	3.57	2.5

k	4.18	Carers in the intervention group recorded a higher score than the control group for the statement "I understand the nature and causes of my own health condition(s)"	3.04	2.52
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\* DO, V. et al., 2015. Relationships between activation level, knowledge, self-efficacy, and self-management behaviour in heart failure patients discharged from rural hospitals. *F1000Research*, 4 (150), pp. 1-11

#### **4.1.2 Understanding impact created by Living it Up**

The evidence listed in table 1.0 suggests there are several areas of important behavior change impact indicated in this study from LiU, within the following 3 domains.

In the paper, *The behaviour change wheel: A new method for characterising and designing behaviour change interventions featured in Implementation Science* developed by a team at The Kings Fund (2011)<sup>60</sup> (also referred to as the COM-B Model), these three domains are:

- *Domain 1: Capability and motivation* - to be receptive towards and/or to adopt new behaviours and habits regarding health and care routines;
- *Domain 2: Opportunity via social differences* - especially the effect volunteering opportunities and social connectedness have upon an individual to manage better with peer to peer support and/or family and social group support; and,
- *Domain 3: Motivation to trial and/or instigation of alternative behaviour/s and habits in self-care and self-management, including being an 'active health and care citizen/patient'.*

#### **4.1.3 Attributing the importance of Living it Up to the management of long-term conditions and well-being**

During the course of the telephone interviews (n=10), respondents were asked to rate the importance of Living it Up to the management of their long-term condition and to their wellbeing.

For the management of their LTC, active users rated LiU either 'very important' or 'important'.

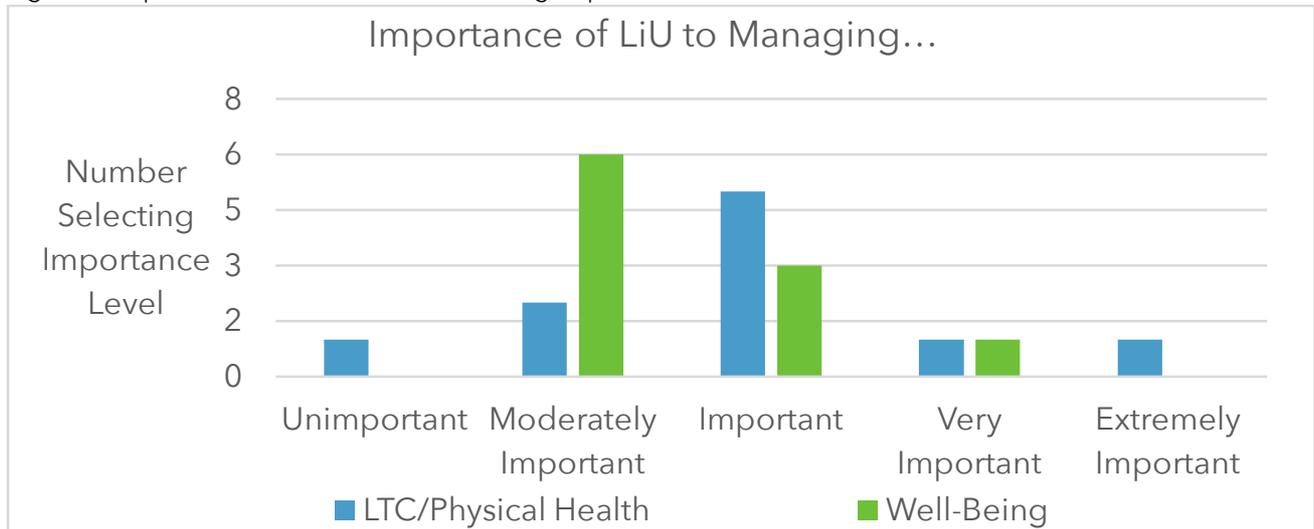
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<sup>60</sup> MICHIE, S., VAN STRALEN, M. M. and WEST, R., 2011. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6(42), pp. 1-11.

For their well-being, the level of importance reported is a more mixed picture of importance.

Figure A illustrates the range of participant responses.

Figure A: Importance of LiU for the Intervention group



#### 4.1.4 Determining specific impacts of Living it Up using a Theory of Change

Theory of Change (TOC) is a highly validated tool used across the globe for tracking and monitoring the impact or difference/s resulting from public services and social programmes.

There are many theories of change that include concepts relevant to capabilities and motivation, social differences and habit formation. A TOC approach has been used in this Chapter to determine and assess the impact of Living it Up.

#### 4.1.5 Applying a theoretical approach to the impact findings

By using a validated, theoretical foundation, an assumption is made whereby indicative findings can be interpreted and aligned to the model that is validated in academic review circles.

For the purposes of this report, the indicative impact findings that are detected by using this theoretical foundation are therefore considered to be interacting at any given time within the 'behaviour change wheel'<sup>61</sup>.

The behaviour system that LiU represents can be ascribed to a validated model called the COM-B system<sup>62</sup>. The COM-B model was used independently in 2010 by the UK Government's tobacco control strategy policy development people and then again earlier in 2006 by the National Institute for Clinical Excellence to generate obesity guidance<sup>63</sup>.

The 'COM-B' system is an acronym used to represent factors of Capability, Opportunity and Motivation leading to Behaviour<sup>64</sup>.

*Capability* is defined as the individual's psychological and physical capacity to engage in the activity concerned. It includes having the necessary knowledge and skills<sup>65</sup>.

*Motivation* is defined as all those brain processes that energise and direct behaviour, not just goals and conscious decision-making. It includes habitual processes, emotional responding, as well as analytical decision-making<sup>66</sup>.

*Opportunity* is defined as all the factors that lie outside the individual that make the behaviour possible or prompt it. The single-headed and double-headed arrows in Figure 1 represent potential influence between components in the system. For example, opportunity can influence motivation as can capability; enacting a behaviour can alter capability, motivation, and opportunity<sup>67</sup>.

Figure 1. features illustrate the domains and their interrelationships with one another within the COM-B model.

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<sup>61</sup> MICHIE, S., VAN STRALEN, M. M. and WEST, R., 2011. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6(42), pp. 1-11.

<sup>62</sup> MICHIE, S., VAN STRALEN, M. M. and WEST, R., 2011. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6(42), pp. 1-11.

<sup>63</sup> NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE (NICE), 2006. *Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children*. London: NICE.

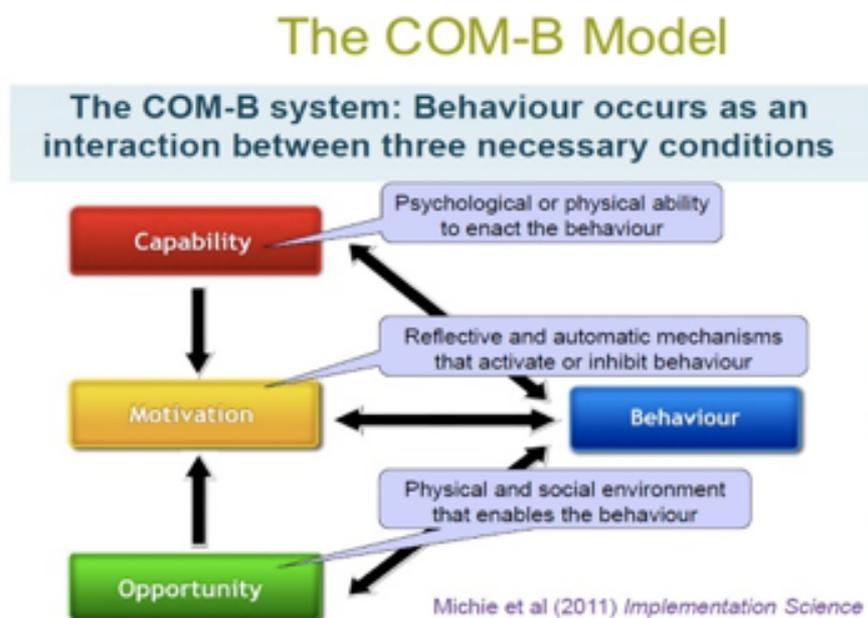
<sup>64</sup> MICHIE, S., VAN STRALEN, M. M. and WEST, R., 2011. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6(42), pp. 1-11.

<sup>65</sup> MICHIE, S., VAN STRALEN, M. M. and WEST, R., 2011. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6(42), pp. 1-11.

<sup>66</sup> MICHIE, S., VAN STRALEN, M. M. and WEST, R., 2011. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6(42), pp. 1-11.

<sup>67</sup> MICHIE, S., VAN STRALEN, M. M. and WEST, R., 2011. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6(42), pp. 1-11.

Figure 1. Diagram of the COM-B Model for behaviour change



SOURCE: Implementation Science (2011)

Indicative findings from the LiU cohort study are now collated within each domain of the COM-B model

#### **4.1.6 1. Significant findings aligned to the capabilities and motivation domain**

Many psychological theories identify motivation as an important behavioural determinant. According to The Kings Fund, the definition of 'motivation' is 'the psychological forces or energies that impel a person towards a specific goal' (Sheldon et al 2003)<sup>68</sup>.

Motivation can therefore be used positively to determine impact for LiU because it refers to both a reason and innate/personal capability that can adjust action and/or generate trial of adjusted self-management and self-care in those with a LTC<sup>69</sup> and/or carers.

Quotes from respondents in the speech bubbles below are illustrative of the significant findings for capability and motivation levels.

<sup>68</sup> SHELDON, K. M., WILLIAMS, G. C. and JOINER, T., 2003. *Self Determination Theory in the Clinic. Motivating physical and mental health*. New Haven, CT: Yale University Press.

<sup>69</sup> DIXON, A., 2008. *Motivation and Confidence: what does it take to change behaviour?* [online]. London: The Kings Fund. Available from: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_document/motivation-confidence-health-behaviour-kicking-bad-habits-supporting-papers-anna-dixon.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_document/motivation-confidence-health-behaviour-kicking-bad-habits-supporting-papers-anna-dixon.pdf) [Accessed February 2016].

Chris (IR2) - Feels very determined

"Up my exercise periods by 10 minutes a day. Eat less biscuits. Go to bed before 3 a.m."

Edith (IR3) - Feels very determined

"I am going to look after 3 grandchildren while their parents are in London for 3 days. Looking forward to it mentally but they will take their toll physically."

The findings suggest that a greater sense of personal control reported by respondents is not necessarily correlated with improved levels of well-being.

Indicatively, this appears to be the case for active users even when those managing their LTC are connected with family, friends, colleagues and neighbours and spend time developing these relationships, and are open to learning and leading more active lives.

Sarah (IR8):

"I'd say I've been managing exceptionally for a long-time given what I face day to day. Sometimes I feel like I'm doing a bit of a crap job but mostly, I know I do a good one... I also know myself, I feel mentally happy when I know others are close-by. I suppose that's why I am now going to be volunteering."

#### 4.1.7 2. Social differences via community and peer group opportunity

NHS Choices suggests that volunteering and social connectedness can improve a person's coping skills and social resilience to overcome challenging situations as well as an individual's well-being<sup>70</sup>. It is also evidenced that giving to others is known to stimulate the reward areas in the brain, creating positive feelings<sup>71</sup> and can also give people a sense of purpose and increased feelings of self-worth.

For LiU, active users recorded higher levels of volunteering and community activity than the control study group (see table below).

Table A: Number of participants partaking/seeking volunteering opportunities

<sup>70</sup> NHS CHOICES, 2014. *Stress, anxiety and depression: Give for mental wellbeing*. [online]. London: NHS Choices. Available from: <http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/give-for-mental-wellbeing.aspx> [Accessed February 2016].

<sup>71</sup> NHS CHOICES, 2014. *Stress, anxiety and depression: Give for mental wellbeing*. [online]. London: NHS Choices. Available from: <http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/give-for-mental-wellbeing.aspx> [Accessed February 2016].

	Number of individuals partaking/seeking in volunteering	
	Control	Intervention
Onset of study	0	2
By study conclusion	1	4

A. Bethany (IR1):

"I go to the over 50's club 2-3 weekly. I found out about the Club on Living it Up and then someone by chance in my [friendship] circle, said they were going to give it a try [if I did]. We do lots of different things. Yesterday we went to see a play at Eden Court and it only cost £6.00 each. I'm in touch with the Alzheimers Society also because I volunteer for them on their Board."

#### 4.1.8 3. Trial and/or instigation of alternative behaviour/s and habits

Findings that directly relate to Hibbard's patient activation model in the primary research and those reported in relation to both positive and negative situations were explored with the telephone interviews.

The qualitative findings demonstrate that there are a number of significant and, near significant impacts or differences in coping, social resilience and self-care and self-management, between active users and non-users of LiU in the study.

Many of these relate to trial and or actioning specific behaviours. See Appendix D for summary analyses of the telephone depth interview data from the control and intervention samples.

Sarah (IR8):

"I plan my life around others being around like my care assistant or my boyfriend and friends. That's how I work it. I'd love more energy. But having longer time with my social care person will help me access a hospital appointment for 20-minutes with the Thyroid Specialist from home [using online access to NHS services]. What a great thing that would be for me."

Wallace (IU10):

"I love walking on the beach but it's a bit of a drive so I don't get to do it often. I get frustrated that I can't do walking and the gym all of the time, but I do enjoy the gardening and if I get to a place where I can do that part-time then I will."

Susanna (IR7):

"I am a regular walker. I really like it and I feel bad about myself when I don't have time to do it. Since doing the diary exercise, I am proud to say that I have not been to hospital, a nurse or a GP during the period of the diary completions. Perhaps I've done a lot more than I think!"

Beliefs about the effectiveness of the behaviour/s active users were trialling or conducting regularly and, the social influences including social norms, social support or pressure, and the behaviours of others (Bandura 1997)<sup>72</sup> that effected them.

Figure B shows a graph illustrating a significant finding for carers (n=4). Whereby carers within the active user group 'had attempted a new caring technique or did something new for the person they cared for' during the study period. The mean score for this group was 5.5. In contrast, carers in the control group (n=3) reported a mean of 0.75 for trialling a new technique.

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<sup>72</sup>BANDURA, A., 1977. Self-efficacy: toward a unifying theory of behavioural change. *Psychological Review*, 84(2), pp. 191-215.

Figure B: Mean scores of carers for the statement “Tried a new caring technique or did something new with/for the person I care for”

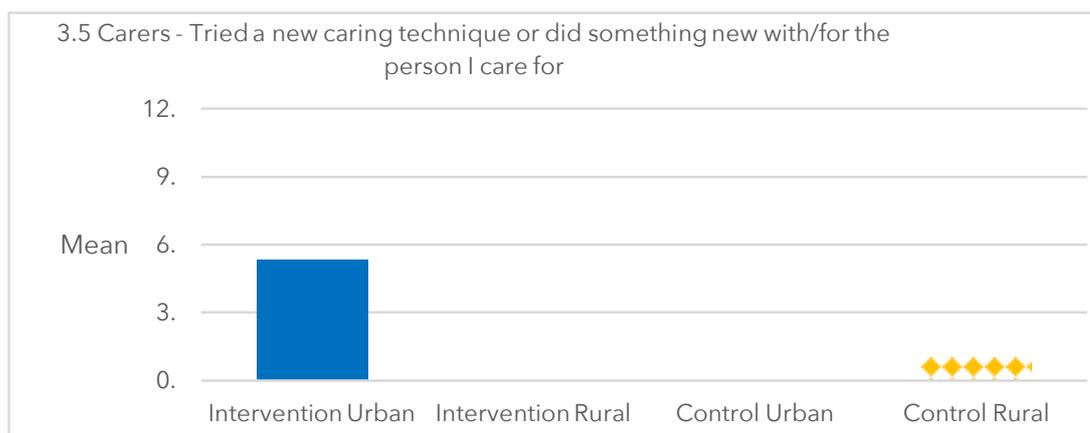
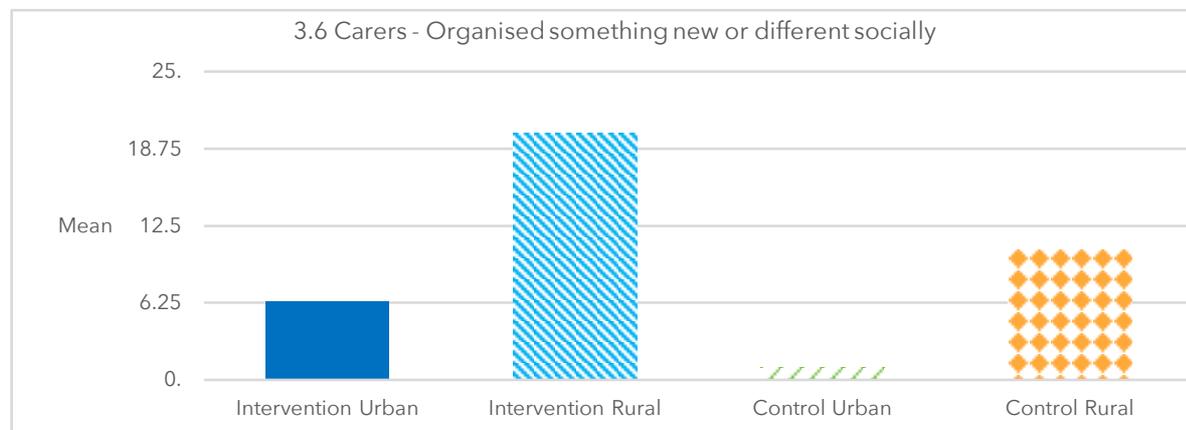


Figure C below illustrates a significant finding for carers (n=4), whereby carers within the active user group ‘had organized something new or different socially’ during the study period. The mean score for the rural carer intervention group was 20. In contrast, carers in the rural control group (n=3) reported a mean of 10.5 for organising something new or different socially.

Figure C: Mean score of carers for the statement “Organised something new or different socially”



Please see sample quotes that highlight behaviours in self-care and self-management in table B below. This table highlights distinctions evident between non-users and active users of LiU.

Table B Sample quotes that highlight the distinctions between non-users and active users of Living it Up

GROUP	RESPONDENT DEMOGRAPHIC & LOCATION PROFILE	LONG-TERM CONDITION	UNPROMPTED QUOTE IN DIARY AND/OR DURING TELEPHONE INTERVIEW DEMONSTRATING BOTH HIGHER LEVEL OF ACTIVATION ON SCALE THAN CONTROL GROUP AND USE OF LIVING IT UP
<b>INTERVENTION i.e. using Living it Up 2+ times per month</b>	Rural/island Female Aged 60-69 Volunteering Retired	Diabetes Thyroid Auto-immune system condition Mobility issues Registered disabled	"I spent over 8 hours in a community ambulance being taken to and from the mainland to see my neurologist consultant. When I said to him at the end of the our 20-minute appointment that it would be far less exhausting and more convenient for me to have met him via video conferencing - I'd seen it on Living it Up's newsletter that folk were doing that in other parts of Scotland, he replied: <i>'Do you think I would be learning how to do that?'</i>
<b>INTERVENTION i.e. using Living it Up 2+ times per month</b>	Urban Male Aged 50-59 Self-employed	COPD resulting from Lung Transplant operation in 1996	"I've become really active in the Walking Group locally. I saw it on Living it Up some time ago last year and I've made friends doing it. I take the classes that are recommended for COPD carers locally and I do that about 6-times a year because my wife had a kidney transplant and I care for her also. It's a team thing. When I need [caring for] she is there for me and vice-versa. But before I joined the walking group, I couldn't even walk the dog. I now walk far faster and longer and it just takes my mind off [the worry] about what could happen next for a short while. It helps me concentrate too when I am fishing with my friends"
<b>INTERVENTION i.e. using Living it Up 2+ times per month</b>	Rural/mainland Female Aged 60-69 Working	Diabetes Thrombocytopenia (Blood platelet condition)	"I've been managing a long-term health condition - my platelet condition - for over 11-years. So when I was diagnosed with diabetes about 18-months ago I thought I would get the same expert advice and support for diabetes. And to be honest, I feel that I have been cut adrift from my dietician nurse and GP. I need them to treat me not just my blood sugar" to get it under better control. For example... I've always had a really good diet and hobbies and friends. And I've been struggling to find consistent information that gives me a guideline about what I should be doing each week to control it other than '[my GP telling me to] take tablets'. I'd been looking for a while on the Internet - and I work with older people so I know the usual haunts to look - and I stumbled on Living it Up.

			So far [their advice] has been the only thing that seems to have fitted into my life"
<b>CONTROL i.e. non-user of Living it Up, independently recruited</b>	URBAN Female Non-working Aged 60-69	Asthma and Arthritis	"The doctor is proactive and rings me from time time to time.....He calls me, he gives me a MOT checkup - checks the tablets are working, the bloods are taken. We have a fab Nurse. We have known Joan for a number of years. She has twins, one is a doctor and one is a lawyer. She does the blood pressure for my asthma..... I must be going alright"  "I have lost a bit of weight, but it is not easy. Sometimes I try and put some on, and get it off, the doctor doesn't nag me about it. He knows I tries. It's hard over Christmas".
<b>CONTROL i.e. non-user of Living it Up, independently recruited</b>	Rural Female Age 60-69	High blood pressure and High Anxiety	Participant suffered from unexpected nose bleeds during the course of the study in the middle of the night. Cauterisation of nose after excessive blood loss - went to A&E three times.  "The doctor is very good at keeping an eye on me. The A&E - weren't good, they just told me you have stopped bleeding now and you go home. But they didn't say anything about the blood pressure being high. They didn't check it. 3 times they sent me home. I felt awful, it was middle of the night. I couldn't understand it. I was really worrying about it"
<b>CONTROL i.e. non-user of Living it Up, independently recruited</b>	Rural, Male Recently Retired	Asthma - from early childhood (whole life) and recently diagnosed high blood pressure	"My asthma is managed pretty well by the medication I take, I have been on it a few years. I take a preventer so I have the relief, but I rarely need to use it. The steroid based inhaler manages it for me pretty well on a day to day basis. There is the odd time I do forget but I am conditioned as I have had since I was two years old. I am very much aware that it is something I do need to take all the time, and it helps me lead a normal life I would say. "My wife looks out for any triggers for me, like feathers in hotel pillows"
<b>CONTROL i.e. non-user of Living it Up, independently recruited</b>	Urban Female Not working	Diabetes Type 2 Obesity Leg ulcers Disability permit	"I can't be bothered to go to the doctor every day to get the dressings on me. It's an effort and it's hard to even get dressed to get the shoes on. I can't get them on my feet. I need a special shoe on my left foot. Hard to walk, uneven pavements, you need assistant to walk to somewhere. And everyone stares at you, you know"

## 4.2 Impact areas for Living it Up

If the indicative findings in table 1.0 are collated within a theory of change using the COM-B model, then the impacts inferred for active users with LTCs and/or carers aged over 50 are:

- A. Self-management of long-term conditions like routine adherence for LTC self-management and only visiting a care service or health setting when needed;
- B. Self-care of one's self via motivation and information to look after themselves when they can;
- C. Goal setting like planning around obstacles and setting up positive plans to care, be social or maintain physical activity;
- D. Self-efficacy or self-belief when navigating around unforeseen or planned problems in regards to the level of health and care support given to their LTC, new diagnoses and changes physical health;
- E. Activation of care and health customers and patients via improved care choices to become 'expert patients'; and,
- F. Volunteering/community work including social connectedness.

Areas A-F are now discussed and illustrated via the use of quotes, vignettes/case studies and graphs.

### 4.2.1 A. Self-management of long-term conditions

Primary research suggests that once long-term conditions are diagnosed, that active users of LiU seek additional lifestyle information. Such information and/or support is not usually available or easily accessible from the health and care professionals they may be in contact with at the time of diagnosis or when their conditions change.

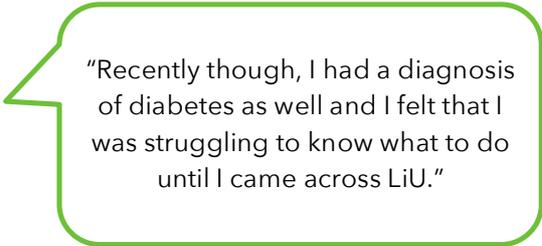
The following case study demonstrates this and the role that LiU plays in supporting the active user to manage both of her long-term conditions when living in a rural setting.

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#### **Susanna - IR7**

##### Condition/Caring Status

Susanna has had her thrombosis blood condition for many years but has recently been diagnosed with diabetes.



"Recently though, I had a diagnosis of diabetes as well and I felt that I was struggling to know what to do until I came across LiU."

### Goals

Having recently been diagnosed with diabetes Susanna is determined to learn more about how to control and handle her condition as well as her thrombosis.

"They are literally looking at 10-minute appointments. And I wanted to know about what to eat, when I should do it, how the testing actually worked. It just wasn't there. I wanted to know how to live."

### Living Context

None of Susanna's family help her directly with her condition due to not living close by. Susanna has annual and bi-annual contact with her GP and diabetic nurse and felt that the initial advice and appointments regarding her diabetes were far too brief and very confusing.

"I'd like to join a group of others who have diabetes to talk about it. I think that would help... Your diary though gave me something to think about and I might just do it now."

### Community Context

Susanna doesn't have any contact with voluntary or charity organisations but is keen to join a group who also has diabetes so she can discuss and learn about her condition.

"I want to understand things and how things work. I need knowledge to do that and that's what's been missing a great deal of since my diabetes condition."

### Tools and Skills

There is no direct mention from Susanna about tools and skills but she does enjoy her work and enjoys her hobbies and appears to be managing her thrombosis well but is struggling with her diabetes.

"I do think about things I can do in future that will help me. Like cooking a new recipe that will maintain by blood sugar levels. Making plans to see a friend or when I go to my book club."

### Outcomes/Changes

Susanna has realised that she wants/needs to be more social. She really enjoys her needlepoint and quilting but does realise it is a lonely hobby. In the future Susanna wants to learn recipes that help her to control her blood sugar levels. Also she wants to increase her knowledge about her condition.

"The Internet is my biggest source of information about my condition but especially about my diabetes right now. Living it Up a bit more than other sites because of the range for MY LIFE it gives me."

When symptoms change for those with long-term conditions, it is reported that there is little trusted and safe information that can advise you 'how to live your life better'.

It is also reported in some cases that those with LTCs and/or carers aged over 50 believe that it is not really the role of their health and care professionals to support them to develop and support their hopes and plans of living well with a long-term condition/s.

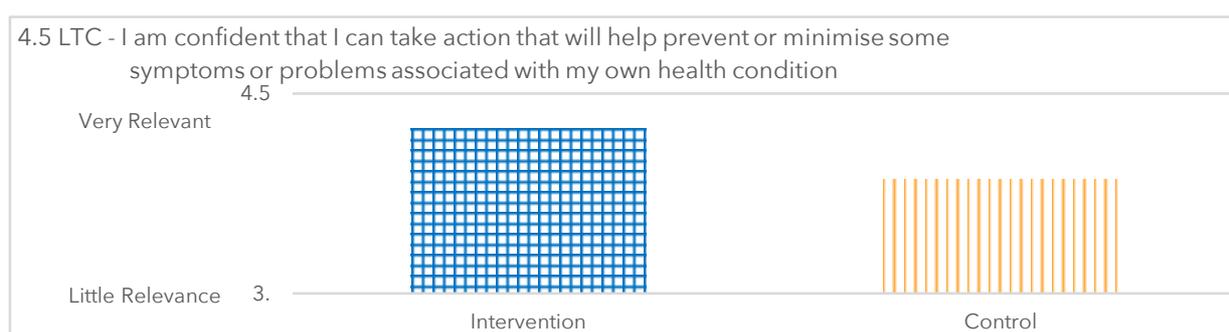
Wallace (IU10):

"When you're first diagnosed, you don't really know what the rules are or where to turn to. I suppose that's why I like LiU. I could see all of the things that I did do back then but didn't know it was the right thing at that time."

Findings also suggest that those that actively use LiU can take action that will help prevent or minimise symptoms or problems associated with their own health condition.

Figure D below illustrates the mean score (4.2) for active users when answering the PAM statement: 'I am confident that I can take action that will help prevent or minimise symptoms or problems associated with my own health condition' by the intervention group (n=18). The mean score for the same PAM statement for the control sample is (3.9).

Figure D: Graph showing the mean score for the intervention and control groups for the Patient Activation Model statement: 'I can take action that will help prevent or minimise symptoms or problems associated with my own health condition'



#### 4.2.2 B. Improved motivation and sustained self-care

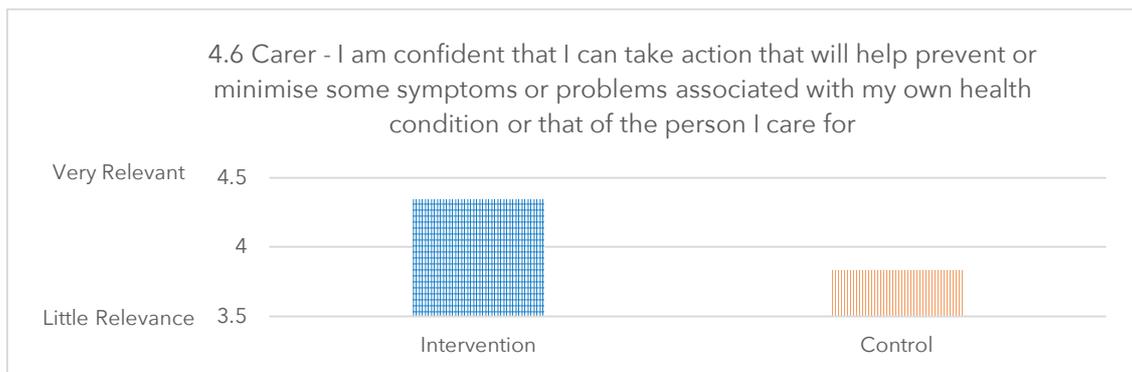
Empowering people with the confidence and information to look after themselves when they can, and visit the GP when they need to, gives people greater control of their own health and encourages healthy behaviours that help prevent ill health in the long-term. In many cases people can take care of their minor ailments, reducing the number of GP

consultations and enabling GPs to focus on caring for higher risk patients, such as those with co-morbidities, the very young and elderly, managing long-term conditions and providing new services.

Findings in this study suggest that those actively using LiU can take action that will help prevent or minimise symptoms or problems associated with their own health condition.

Figure E below illustrates the mean score (4.3) for carers when answering the PAM statement: 'I am confident that I can take action that will help prevent or minimise symptoms or problems associated with my own health condition' by the intervention group (n=19). The mean score for the same PAM statement for the control sample is (3.8).

Figure E: Mean score for the intervention and control groups for the PAM statement: 'I can take action that will help prevent or minimise symptoms or problems associated with my own health condition or that of the person I care for'



The following vignette illustrates the thought and action processes from an active user to improve his motivation when experiencing severe pain and sustain his care routine.

**Walter - IR9**

Condition/Caring Status

Walter suffers from arthritis and prior to using LiU continued to suffer pain and discomfort while on medication. Since using LiU he has completely changed his diet and no longer needs to take medication for pain relief.

"I read on Living it Up that when some people adjusted their diet that it helped their pain levels. So I started to try it because I was desperate."

### Goals

Over the festive period Walter's diet slipped and meant that his arthritis flared up again so he wants to be better at sticking to his diet during celebration times.

"When I think of times that I am tempted to drift off my diet, like holidays, I soon feel my pain and sluggishness coming back if I do [let the diet go]. So I think about what I can do each day to keep as much of the diet as possible going. It's about doing a little bit at a time"

### Living Context

Walter has a strong connection with his family, going swimming with his grandchildren but also walking the dog almost every day and he volunteers. Walter didn't used to walk the dog much before he changed his diet but now walks the dog each day even on bad days when pain returns.

"My contact with my GP is far lighter than it used to be. Ever since I've done this new diet for the last 2-years, it's been an occasional visit. The last time I went to the was for a flu jab.

### Community Context

Walter is heavily involved with community and social projects such as the 'Fish Problems Club' which is a global forum and Urban Workers Falkirk to do litter picking and clearing woods.

"I volunteer with Urban Workers. It's a woodland charity in the area. We do litter picking and removing invasive species, we prune bush tree in local parks. I've also reconnected with my buddies that fish, so I'm doing that a lot also"

### Tools and Skills

The main tool/skills that Walter uses is trial of new techniques and behaviours by setting tiny steps and goals; particularly where changes to his diet are concerned, which came from advice on LiU. This is bolstered by social mobility and volunteering opportunities. These changes combine to positively effected Walter's LTC self-management.

"I used to be a misery to live with and I don't know how my wife put up with me when I look back. It's definitely the right thing - to get up off your backside and get on with it."

### Outcomes/Changes

After seeing information on LiU on about how diet can help alleviate some aspects of Walter's condition he drastically changed his diet and has since been able to stop taking his medication. He has also reconnected with fishing (an old hobby) which was again due to advice from LiU.

"I now eat wholefoods and avoid processed foods wherever possible. I cook a lot for me and my wife. It's eliminated the pain for me and I no longer take medication. I just feel more people should know about this"

Giving patients the information they need to feel equipped to care is reported as a priority for those with long-term conditions and/or carers aged 50 and over living in Scotland.

How to care for their common ailments and the 'everyday' is viewed as important to respondents.

For example, how long it might take (realistically) to overcome a common cold when you have a long-term condition or experience worsening symptoms is viewed important.

Molly (IU8):

"There are times I don't want to go out the front door but I then think I know I'm going to feel better if I do go and see everyone."

#### 4.2.3 C. Goal setting

Goal setting is pivotal to behaviour change and adjustments of managing a long-term condition according to the Centre for Outcomes Research and Effectiveness, Department of Psychology, University College London in 2004<sup>73</sup>.

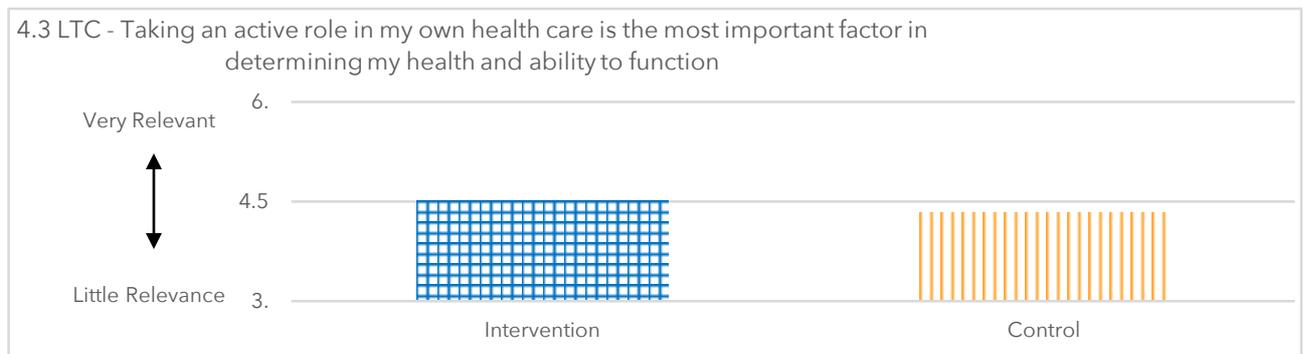
Walter (IR9):

"Setting myself little challenges is definitely how I got rid of my pain and off all of those pain-killers... I volunteer with Urban Workers. It's a woodland charity in the area. We do litter picking and removing invasive species, we prune bush tree in local parks."

Figure F below illustrates the mean score (4.5) for active users when answering the PAM statement: 'taking an active role in my own healthcare is the most important factor in determining my health and ability to function' by the intervention group. The mean score for the same PAM statement for the control sample is (4.3).

<sup>73</sup> MICHIE, S., et al., 2005. Making psychological theory useful for implementing evidence based practice: a consensus approach. *Quality Safety Health Care*, 14, pp. 26-33.

Figure F: Graph showing the mean score for the intervention and control groups for the Patient Activation Model statement: 'taking an active role in their own health care was the most important factor in determining my health and ability to function'



Susanna (IR7):

"I want to understand things and how things work. I need knowledge to do that and that's what's been missing a great deal since my diabetes condition. I do think about things I can do in future that will help me. Like cooking a new recipe that will maintain by blood sugar levels. Making plans to see a friend or when I go to my book club."

The next case study demonstrates the role that LiU plays in supporting an active user to set goals and manage multiple long-term conditions when living in an island setting.

### **Sarah - IR8**

#### Condition/Caring Status

Sarah suffers from co-morbidities, Home-Addison Syndrome leading to osteoarthritis, unstable walking/balance and sight problems.

#### Goals

The main goal for Sarah is to ensure that she gets

"I would say that I'm exceptional at looking after my health condition because no-one else is helping me. You wouldn't believe what I've been through and still am going through to get services to try and support me."

her care services organised due to companies passing her on due to her health needs. Also she does not want to go to hospital due to many people picking up more illnesses etc.

### Living Context

Sarah does not live near her family so it takes effort to see them and they do not believe that she is ill. She has very little faith in her GP and focuses on getting help from the mainland but in total has had 6 health service visits over the diary period.

### Community Context

Unfortunately, Sarah is unable to get any support from charities or voluntary services where she reports "not to meet the parameters of being 65+ and/or disabled".

### Tools and Skills

Sarah is very keen to gather knowledge and learn in order to help her manage her condition by setting goals and plans around her care so she can do what she can to support herself.

### Outcomes/Changes

Sarah is seriously considering moving to the mainland in order to access more support and services that LiU has made her aware of. The diary exercise has also made her aware that she wants to be more social and that self-directed support is isolating her.

"The Consultant is on the mainland and my GP is a chump. I really have next to no time for him or the local care services."

"There is no voluntary service on the island for me and my condition. They are all for over 65s or for the disabled."

"I was reading LiU one-day and I saw that you can see your GP or consultant by SKYPE OR SOMETHING SIMILAR. I spent 8-hours in a community ambulance to see my consultant for 20-minutes. He said: 'Don't think I'll be doing that for you? I'm no good with those things.' I'll keep asking."

I am exhausted with social and health service and I might have to move to the mainland because I can see on Living it Up that there are lots of things I can use and tap into there but very little here. It's something I am seriously contemplating"

"I like to feel part of the community I've learnt that from Living it Up. It's something they stress quite a lot."

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Self-regulation theory also suggests that individual feedback on one's progress can be helpful to maintain behaviours, such as tools that allow people to track their weight or

physical activity (e.g., pedometers), or that demonstrates health gains in other ways (e.g., lower blood pressure, improved lung function).

#### 4.2.4 D. Self-belief and self-efficacy

While the concepts of confidence and motivation leading to adjustments in behaviour/s are distinct, they are also relational to one another. Evidence gathered within the evaluation points to a relationship being reported by active users of Living it Up that features more prominently in the intervention group than the control group.

The following case study demonstrates the role that LiU plays in supporting an active user to manage multiple long-term conditions when living in an urban setting.

#### **Wallace - IU10**

##### Condition/Caring Status

Wallace is a liver transplant patient but he also cares for his wife who receives support but they mainly leave Wallace to himself due to managing his condition well.

##### Goals

There are no specific goals set out by Wallace but he does like to manage his condition himself due to issues with a GP and a failed diagnosis.

##### Living Context

Wallace lives with his wife and has members of the family close by but he doesn't involve them with his health. He has little contact with GP's and hospitals having only been twice in the whole diary period.

##### Community Context

Wallace is part of the local Carers Association for his wife's care and feels it is beneficial for his wife as well as himself.

"I've been feeling well of late. I'm always quite pleased when I'm asked questions about how I'm doing from people like you. It makes me feel good about how far I have come."

"As I mentioned my experiences of GP advice was so bad a couple of years ago it nearly killed me. I ended up with a collapsed lung thanks to them. He didn't diagnose what I got and I nearly ended up dead. I wouldn't trust anything that a GP - in fact anyone - unless they knew what they were doing with transplants again."

"It gives me a good perspective on her care as well as my own. Its good to share tips and help when we meet up."

"'You're always seeing the positive.' My wife always says that."

### Tools and Skills

Self talk is a skill Wallace uses to improve how he is feeling even when he is feeling low. No other tools or skills were mentioned but Wallace felt that the diary exercise motivated him and was useful for reflection.

### Outcomes/Changes

Wallace now remembers a lot more information about his condition compared to when it originally occurred. This has allowed him to manage his condition a lot better but he does admit that sometimes he pushes himself too hard. Although he does not trust GPs in regard to his condition Wallace does trust his consultant and listens to his advice and supplements it with information he learns.

"It's just about knowing how far you can push it and saying a "positive no". That takes time to feel comfortable with. When you're first diagnosed, you don't really know what the rules are or where to turn to. I suppose that's why I like LiU. I could see all of the things that I did do back then but didn't know it was the right thing at that time."

"I am always quite pleased when I'm asked questions from people like you about how I do. It gives me a buzz to think about how far I have come. Especially on the good days."

Wallace (IU10):

"Even when I'm ill I know I'll come out of it sometime. I feel miserable, but I could feel a lot worse. I find myself saying tomorrow I'll be able to have a bath. Next day I might say that I'll rest and the next day I might say that I'll ring someone to chat about life. Just do something than staring at the same four walls when I'm ill."

Motivational factors and self-efficacy have both been identified as being important in intention formation that is, an individual's commitment to perform a specified behaviour. Intentions express a person's motivation to achieve a specific goal. Intentions in turn are associated with behavioural outcomes, though self-efficacy is believed to have an independent influence on behaviours beyond its role in shaping intentions.

We can see many of the characteristics that Bandura lays down for the improvement of self-belief being the case for many of the intervention respondents in the evaluation.

#### **4.2.5 E. Activation of care and health customers and patients via improved care choices**

Evidence gathered in the evaluation also points to active users being motivated to change or having greater levels of confidence and determination to become more proactive with their care or health professionals to improve their long-term management of their long-term condition or to ease the burden on them, the community, institution and care services.

Once active users of LiU had decided to take more proactive action, they reported that self-belief/efficacy was an important factor in maintaining the effort required in being activated with care or health services and coping with barriers that arise. Therefore, LiU's bolstering of motivation and confidence is important to active users when or if their intentions are to be translated into actual behaviour change.

#### **Elizabeth (IR3)**

##### Condition/Caring Status

Schloriosis suffers from co-morbidities, including pain and osteoarthritis, unstable walking/balance.

##### Goals

The main goal for Elizabeth is to ensure that she completes the application for her education course and manages her life around the pain. She currently has severe prolapsed discs in her back and is experiencing 'some mobility problems',

##### Living Context

Elizabeth lives by herself and social interaction is reported to be key to her enjoying life when she can. She has a brother-in-law who helps her and reports to only visit the GP when she needs to get a top of taking pain killers. In recent years, she took herself off morphine and then tramadol which she reports as 'being very hard but she felt muddled and wanted to change'.

##### Community Context

Elizabeth is seeking to lead a "defenders'

"I don't let [the pain] get on top of me. There are others worse off than me. I phone someone if I get down with the pain. It takes my mind off it"

"I keep busy because it takes my mind off the pain. I do lots of things to keep going"

"I read up on everything to get myself off that stuff. I was losing out on life. That's how I came across Living it Up. I have a good GP but was refused surgery. I'm now attending a pain clinic in Golspie so I can manage in a different ways"

community support initiative to alleviate her loneliness during the day and get to know others in her community.

### Tools and Skills

Elizabeth searches for information when she wants to change things in her life and if one route is blocked, she finds another. Problem-solving is an important tool as is goal setting.

"Living it Up said that I could train as a volunteer and become a "defender". I looked more into it and its about giving up your house a few mornings or afternoons a week and 'becoming a 'drop-in' for other lonely people with pain and other health issues. I've got the pack and I am applying things."

### Outcomes/Changes

Elizabeth is seriously considering moving to the mainland in order to access more support and services that LiU has made her aware of. The diary exercise has also made her aware that she wants to be more social and that self-directed support is isolating her.

"Defenders seems right for me. I looked up other things I could do but that seemed the best thing to fit around my pain clinic attendance"

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Equally, the intervention group reported slightly higher scores using the Patient Activation Model for the statement: *"I feel confident asking questions of my health/care professional even when I have not been asked"*

#### **4.2.6 F. Volunteering/community work including social connectedness**

Active users of LiU recorded far higher rates and broader areas of volunteering and community activity when compared to the control group.

Therefore, sign-posting, encouragement and take up of social constructs such as volunteering, community and club activity plus the online interactive tools to identify someone's talents and skills for example, is intrinsic to LiU's support of those with long-term conditions and/or carers.

The case study below demonstrates the role that LiU plays in supporting an active user to manage multiple long-term conditions when living in an urban setting.

## **Bethany - IR1**

### Condition/Caring Status

Bethany suffers from Chronic Rheumatoid arthritis and has had finger joints, knee and hip joints replaced.

### Goals

Bethany's main goal is to not get admitted back into hospital. It is also to stay as healthy as possible due to her health impacting on her husband's well-being.

### Living Context

Bethany's husband cares for her and she has a close group of friends she socialises with a lot. She had personal care in the past before the joint replacements due to being unable to perform simple tasks such as getting out of a chair or bed unaided.

### Community Context

Bethany attends an over 50's club 2-3 times a week as well as being in touch with Alzheimer's Society.

### Tools and Skills

She uses a lot of simple tips to help prevent her falling/ dealing with her arthritis which makes a large impact on her day to day life. Another tool is her contact with her 50+ club (through LiU) which not only gives her support but also advice and tips.

### Outcomes/Changes

Bethany is determined to not let the fear of falling take grip again and prevent her from being independent/enjoying her life. Her over 50's class

"I have good days and I have bad days. I get frustrated because I can't do as much and I am reliant on my husband."

"I've been to see my GP twice in the past two months... I also see an OT every 3 months."

"I go to the over 50's club 2-3 weekly. I found out about the Club on LiU."

"I don't tend to think about the pain and my lack of movement if I've having a gossip and a natter. Laughing is therapy in itself."

"Things I've learnt which will keep me in good stead are thing like boiling potatoes with a frying basket so I can lift the potatoes out of the pan without having to lift the heavy pan of water."

(found on LiU) also helps her forget her pain due to laughter and conversation. Completing the diary study has also made Bethany aware of how well she is doing recovering from her fall and that has given her confidence to keep doing what she is.

“Everyday tips that are just helping you live safer and free from the fear of falling again. It’s a real fear when you’re my age.”

## 5.0 ACCESSIBILITY OF LIVING IT UP

### 5.1.1 How this chapter is structured

This chapter details the standards, methods and definitions in terms of understanding the level of accessibility of LiU for active users. Using each guideline, the chapter then gauges the level of accessibility of the online service in detail.

### 5.2 Accessibility guidelines for online services

The guidelines used to gauge the accessibility of LiU for those aged over 50 with long-term conditions and/or carers is based upon the guiding principles of The Government's Service Design Manual specific to Web Content Accessibility Guidelines (WCAG) AA level standard<sup>74</sup>. WCAG is a widely accepted governmental standard that informs and benchmarks digital accessibility for online services like LiU.

As such, the Level AA of the Web Content Accessibility Guidelines (WCAG) 2.0 and W3C that provides Accessibility Evaluation Resources<sup>75</sup> have been used to compile and analyse LiU's level of accessibility and are gauged within the Equality Act (2010).

Table 1.0 Title of reports used in this Chapter to inform accessibility approach

TITLE OF REPORT/SECONDARY SOURCE	Author/s / where report is from/who
UK Government	<a href="https://www.gov.uk/service-manual/user-centred-design/accessibility">https://www.gov.uk/service-manual/user-centred-design/accessibility</a> ).
Web Content Accessibility Guidelines	<a href="http://www.w3.org/WAI/intro/wcag">http://www.w3.org/WAI/intro/wcag</a>
Equality Act 2010	<a href="http://www.legislation.gov.uk/ukpga/2010/15/contents">http://www.legislation.gov.uk/ukpga/2010/15/contents</a>

<sup>74</sup> THE UK GOVERNMENT, 2014. *Accessibility. How to make services that everyone can use*. [online]. London: The UK Government. Available from: <https://www.gov.uk/service-manual/user-centred-design/accessibility> [Accessed February 2016].

<sup>75</sup> WORLD WIDE WEB CONSORTIUM WEB CONTENT ACCESSIBILITY GUIDELINES. THE UK GOVERNMENT, 2014. *Accessibility. How to make services that everyone can use*. [online]. London: The UK Government. Available from: <https://www.gov.uk/service-manual/user-centred-design/accessibility> [Accessed February 2016].

Office for Disability Issues updated Department for Work and Pensions 2009/10	<a href="https://www.gov.uk/government/statistics/disability-facts-and-figures">https://www.gov.uk/government/statistics/disability-facts-and-figures</a>
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## Methods used

Two methods were used by the study team to assess the accessibility of LiU for active users.

The first was the Accessibility Evaluation Resources from the WCAG Guidelines and the second was web analytics which according to the Web Analytics Association, there are three types of Web analytics metrics: counts, ratios, and KPIs<sup>76</sup>:

- *Counts* are the most basic unit of measure; a single number, not a ratio. Often a whole number (Visits = 12,398), but not necessarily (Total Sales = \$52,126.37.);
- *Ratios* are typically, a count divided by a count, although a ratio can use either a count or a ratio in the numerator or denominator. Usually, it is not a whole number. Because it's a ratio, "per" is typically in the name, such as "Page Views per Visit." A ratio's definition defines the ratio itself, as well as any underlying metrics; and,
- *KPIs* (Key Performance Indicator) can be either a count or a ratio, it is frequently a ratio. While basic counts and ratios can be used by all Website types, a KPI is infused with business strategy – hence the term, "Key" – and therefore the set of appropriate KPIs typically differs between site and process types.

A fourth type of definition is included in web analytics for terms that describe concepts for services instead of numbers. For the purposes of Living it Up these are the concepts of quality, health inequality and preventative health routines (such as self-care and self-management). A dimension is defined by the Web Analytics Association as:

- *Dimension* - A general source of data that can be used to define various types of segments or counts and represents a fundamental dimension of visitor behaviour or site dynamics. Some examples are event and referrer.

They can be interpreted the same as counts above, but typically they must be further qualified or segmented to be of actual interest. Therefore, these define a more general class of metrics and represent a dimension of data that can be associated with each individual visitor.

<sup>76</sup> BURBY, J., BROWN, A. and WAA STANDARDS COMMITTEE, 2007. *Web Analytics Definitions*. [online]. Washington, DC: Web Analytics Association. Available from: [http://www.digitalanalyticsassociation.org/Files/PDF\\_standards/WebAnalyticsDefinitionsVol1.pdf](http://www.digitalanalyticsassociation.org/Files/PDF_standards/WebAnalyticsDefinitionsVol1.pdf) [Accessed March 2016].

Web analytics are measured across differing user dimensions. A metric can apply to three different types of user:

- *Aggregate* refers to a total site traffic for a defined period of time;
- *Segmented* refers to a subset of the site traffic for a defined period of time, filtered in some way to gain greater analytical insight: e.g., by campaign (e-mail, banner, PPC, affiliate), by visitor type (new vs. returning, repeat buyers, high value), by referrer and so on; and,
- *Individual* refers to an activity of a single Web visitor for a defined period of time.

WCAG 2.0 is a technical standard that public services online need to meet, and not an introduction to accessibility. It has 12 guidelines that are organised under 4 principles:

1. Perceivable;
2. Operable;
3. Understandable; and,
4. Robust.

For each guideline, there are testable success criteria, which are found at three levels. These are: A, AA, and AAA rated. According to these guidelines, digital services need to assess their web "content" to ensure that it is accessible to the public. The type of content that should be accessible includes:

- Natural information such as text;
- Images;
- Sounds code;
- Format;
- Sizing; and,
- Markup that defines structure, presentation, etc.<sup>77</sup>

WCAG is primarily intended to help the following types of practitioners:

- Web content developers (page authors, site designers, etc.);
- Web authoring tool developers;
- Web accessibility evaluation tool developers;
- Others who want or need a standard for web accessibility; and,

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<sup>77</sup> THE UK GOVERNMENT, 2014. *Accessibility. How to make services that everyone can use.* [online]. London: The UK Government. Available from: <https://www.gov.uk/service-manual/user-centred-design/accessibility> [Accessed February 2016].

- Related resources are intended to meet the needs of many different people, including policy makers, managers, researchers, and others.

### 5.3 Methods used to gauge accessibility of Living it Up

In addition to the guidelines used, the study team has used supplementary methods of web analytics<sup>78</sup> used to compile this Chapter.

These are as follows:

- Review of website visitor statistics supplied by the LiU managed service;
- Comparisons with similar websites; and,
- Verbal communication with the LiU team and a review of the goals and targets published by the LiU project.

The website visitor reports were drawn from Google Analytics and LIU website performance reports. The review period was from January 2015 to January 2016. Readers are invited to note that some statistics were not available for the entire period due to the developing nature of LiU. Analysis of this data within the WCAG Guidelines have produced insights and conclusions relating to Living it Up, how engaging it is and whether set targets have been met.

#### Definition of Web Analytics is assumed

Web analytics is the measurement, collection, analysis and reporting of web data for purposes of understanding and optimising web usage.<sup>79</sup>

Table 1.1 Lists the desk research/secondary sources of evidence used to based these views upon

TITLE OF REPORT/SECONDARY SOURCE	Author/s / where report is from/who	Date
Key stats month on month spreadsheet.	Living It Up	January 2015 to August 2015
LiU Community Engagement Team InsightsandIdeas_aug13v2	Living It Up	1 Aug 2013

<sup>78</sup> BURBY, J., BROWN, A. and WAA STANDARDS COMMITTEE, 2007. *Web Analytics Definitions*. [online]. Washington, DC: Web Analytics Association. Available from: [http://www.digitalanalyticsassociation.org/Files/PDF\\_standards/WebAnalyticsDefinitionsVol1.pdf](http://www.digitalanalyticsassociation.org/Files/PDF_standards/WebAnalyticsDefinitionsVol1.pdf) [Accessed March 2016].

<sup>79</sup> Web Analytics Association Standards committee embarked on an effort to define what was agreed upon as the three most important metrics - Unique Visitors, Visits/Sessions & Page Views.

LiU Community Engagement Team Yr1 report_sept13v3	Living It UP	September 2015
Managed Service Report	Living It UP	April 2015 to July 2015 and January 2016 Report
Site Search spreadsheet	Living It Up	January 2015 to September 2015
Alexa traffic analytics website	<a href="http://www.alexacom">http://www.alexacom</a>	1 Oct 2015. March 2016
Mailchimp Newsletter Service	<a href="http://www.mailchimp.com/">http://www.mailchimp.com/</a>	March 2016
Google Analytics	<a href="https://www.google.co.uk/analytics/">https://www.google.co.uk/analytics/</a>	1 Jan 2015

The underlying assumption is that increasing the quality of website information, online services, tools and interactions will strengthen links between digital interventions and health and wellbeing. The results from the diary exercise provide evidence for this: indicating reduced feelings of loneliness, increased computer literacy and a propensity to try different caring techniques. It was also found that those living with long term conditions were inspired to try new caring techniques and/or to try new things with the person cared for.

There is support for this conclusion in a number of studies and publications; though presently most seem to be based in America (certainly those found via web search). For example, one study looked at how hospitals are using new media applications to increase patient interactions, "Promoting Participatory Medicine with Social Media: New Media Applications on Hospital Websites that Enhance Health Education and e-Patients' Voices"<sup>80</sup> Another called, "User-Driven Healthcare: Concepts, Methodologies, Tools, and Applications", looked at tools and applications that drive behaviour change as well as the use of social support and interaction.<sup>81</sup> The assumption is that there is a future in increased digital self-management in relation to health if the correct tools and approaches are put in place.

<sup>80</sup> GALLANT, L. M., et al., 2011. Promoting Participatory Medicine with Social Media: New Media Applications on Hospital Websites that Enhance Health Education and e-Patients' Voices. *Journal of Participatory Medicine*, 3(e49).

<sup>81</sup> INFORMATION RESOURCES MANAGEMENT ASSOCIATION, 2013. *User-Driven Healthcare: Concepts, Methodologies, Tools and Application*. Hershey, PA: Medical Information Science Reference.

## 5.4 Living It Up Summary traffic statistics

Table 1.2 Google Analytics Statistics January 2015 thru January 2016

<b>Living It Up Google Analytics Statistics January 31st 2015 to January 31st 2016</b>						
Sessions	Users <sup>8</sup>	Page views	Pages per Session	Avg. Session Duration	Bounce Rate	% New Sessions
99,638	60,495	516,573	5.18	00:04:21	53.99%	59.71%

## 5.5 Comparing Living It Up with other health and wellbeing websites

We have no direct access to site traffic figures for competing websites. However, as a useful proxy we can look at the 'Global rank' figures provided by online analytics website Alexa (<http://www.alexa.com>). These should not be considered as reliable statistics<sup>82</sup>. However, they do give an indication of how websites compare on the same metric using the same analytics tool.

Table 1.4 Global rank figures from Alexa<sup>10</sup> comparing LIU with other health and wellbeing sites

Website	Living It Up	Alzheimer's Scotland	NHS Inform	NHS Choices
<b>Global rank (March 5th 2016: last three months traffic)</b>	3,781,742	1,278,056	694,671	2,171

## 5.6 What can the LIU visitor statistics tell us

The following speculative conclusions are drawn from an analysis of the statistics provided by the LiU project team and access to Google Analytics for the site using data supplied between January 31<sup>st</sup> 2015 and Jan 31st 2016.

<sup>82</sup> ALEXA ANALYTICS WEBSITE [online] Alexa compiles their statistics from the users who have the Alexa toolbar installed in their browser; Alexa then tracks the activity of those users. We do not have any data on the number of people who have the Alexa tool installed but we would speculate that it is likely to be a small percentage of all Web users. Available from: [http://www.alexa.com/about?ax\\_atid=1328bf9c-448b-444f-ba6d-3a120bba5e90](http://www.alexa.com/about?ax_atid=1328bf9c-448b-444f-ba6d-3a120bba5e90) [Accessed April 5<sup>th</sup> 2016]

### **Visitors to the Living It Up site appear to be finding the site content relevant and engaging.**

Statistics show that bounce rates<sup>83</sup> are comparatively low<sup>84</sup> and people are spending a long time on the site (an average of over 4 minutes<sup>85</sup> - January 2015 thru January 2016: Sourced from LIU management report January 2016.<sup>86</sup>) and page views per visit were high<sup>87</sup>. Longer than average time on site can indicate that visitors are finding the content relevant (i.e. to people with long-term conditions, carers, health professionals) and that they are being engaged by it. However, without asking users directly we cannot confirm this using visitor's statistics alone.

The assertion that LIU is providing high quality content is however backed up by the high number of people opening the LIU newsletters and clicking links within them (high when compared to open rates for newsletters in similar sectors<sup>88</sup>). The graph below is taken from the LIU January 2016 management report and shows high average visits and low to average bounce rates.

It should be noted that the visitor statistics changed markedly from September 2015 onwards; due to increased LIU social marketing. The marketing activity increased new visits (i.e. return visits are lower by comparison), lowered visitor duration and increased bounce rates. The less consistent pattern across the year has made it harder to draw firm conclusions.

For that reason, the insights contained in this report are skewed more towards the pattern shown during the first half of the year, i.e. prior to the marketing push, although when averaged across the year still point in a similar direction.

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<sup>83</sup> Bounce Rate is the percentage of single-page visits (i.e. visits in which the person left your site from the entrance page without interacting with the page).

<sup>84</sup> ALEXA ANALYTICS WEBSITE [online] Available from: <http://www.alexa.com>. The following bounce rate figures are drawn from the website Alexa (<http://www.alexa.com>) as we do not have direct access to Google Analytics for the sites referenced. Alziemers Scotland: bounce rate 68.30% (January 2016), NHS Choices: bounce rate 60.20% (March 2016), NHS Inform 58.10% [Accessed March 2016]

<sup>85</sup> MAYECREATE WEBSITE [online] Available from: <http://www.mayecreate.com>. Analysis of 169 sites by Mayecreate 70% were under three minutes: <http://goo.gl/KOLte2> There is a Benchmarking tool on Google Analytics but we were unable to find a suitable category to compare LIU against, there was no health or wellbeing category. For the category of online communities the LIU was showing time on site as less time than the benchmark. [Accessed March 2016]

<sup>86</sup> ALEXA ANALYTICS WEBSITE [online] Available from: <http://www.alexa.com>. On March 1st 2016 Alexa shows a metric for 'daily time on site of 3.21. Alexa shows NHS Choices as 2.49, Alzheimers Scotland 3:11, NHS inform as 3:10. Google Analytics a figure for average time on page of 1 minute 03 January 2015 thru January 2016. [Accessed October March 2016]

<sup>87</sup> ALEXA ANALYTICS WEBSITE [online] Available from: <http://www.alexa.com>. Alexa shows LIU daily page views per visitor as 3.30, NHS Choices as 2.03, NHs inform as 3.00 and Alzheimers Scotland as 2.70 [Accessed March 2015]

<sup>88</sup> MAILCHIMP NEWSLETTER SERVICE [online] Available from: <http://www.mailchimp.com>. Mailchimp Open rates for different market sectors: <http://mailchimp.com/resources/research/email-marketing-benchmarks/> [Accessed October 2015 and March 2015]



Table 1.5. The image above shows how long people spent on the website and the bounce rate (i.e. people who left without exploring the site after landing on a page). It also shows the change resulting from LIU marketing campaign.

Engaging and relevant content is likely to contribute to the LiU goals of improved and/or adjusted self-managing behaviours, accelerated formation of self-management behaviours and access to public services. The comparatively high time on site and lower bounce rate when taken in conjunction with high newsletter open rates means that it could be argued that the site is highly relevant to meeting these goals. However, as indicated earlier, this would need to be confirmed by speaking to site visitors directly.

### 5.7 Online Site Search

The on-site search statistics (October 2015) support the view that the information needs of practitioners, carers and people with long-term health conditions are being met<sup>89</sup>. For example, the top searches include the terms, walking, telecare, health, dementia, COPD, falls and dancing. Support evidence is provided for this assertion in Appendix E Section.

As with evidence of engagement levels, the relevance of the on-site search terms supports the assertion that visitors are using the site for improved and/or adjusted self-managing behaviours, accelerated formation of self-management behaviours and access to public services.

### Health Professionals are likely using LIU

It is suggested from the statistics related to registrations (February 2015 to August 2015), the authors of the content, the terms used to search on the site, the age demographics of

<sup>89</sup> APPENDIX E: LIVING IT UP ANALYTIC STATISTICS - SUPPORTING EVIDENCE TO ACCESSIBILITY SECTION page 3.

the subscribers and informal discussion with LIU staff, that health professionals are using the site to support carers and people with long-term health problems.<sup>90</sup>

The evidence points to a hypothesis that many of the site visitors are not necessarily just people with Long Term Health Conditions themselves but also health professionals supporting people with long term health conditions. See table 1.6 next for supporting evidence of this.

Table 1.6 Users by type February 2015 thru August 2015 from LIU Key stats month on month spreadsheet.

<b>Audience</b>	<b>Feb-15</b>	<b>March-15</b>	<b>April-15</b>	<b>May-15</b>	<b>June-15</b>	<b>July-15</b>	<b>August-15</b>
<b>Carer</b>	35	60	96	118	136	147	11
<b>Service Provider</b>	115	308	434	574	679	708	29
<b>Personal Use</b>	184	345	714	975	1079	1116	37
<b>Other</b>	242	364	587	671	697	706	9
<b>Unknown</b>	13742	13734	13443	13883	14665	14693	28
<b>Sample size</b>	575	1077	1831	2338	2591	2677	86

We can see from the table above (registered users, February 2015 to August 2015) that, despite the website being aimed at people over 50 with long-term conditions, there was a high number of registered service providers (20% rising to 27% by July 2015) and high number of registered users below the age of 50. (For January 2015 more than 63% of the registered users were below 50). (By August 2015 this had fallen slightly but there were still more than 60% of registered users below the target age of 50 plus)<sup>91</sup>. However, it is worth noting the very high numbers not providing information.

The number of people identified as 'carers' or identified as using the site for 'personal use' is below 50% of those registered (statistics for people saying the site is for, 'personal use' ranges from 32% in Feb 2015 up to 43% in July 2015). This is not to be dismissed of course - as it does tell us that people in the target group are registering.

One anomaly that could also suggest that a lot of professions are using the site is the fact that the most popular key phrase being used to find the site via organic search is the

<sup>90</sup> APPENDIX E: LIVING IT UP ANALYTIC STATISTICS - SUPPORTING EVIDENCE TO ACCESSIBILITY SECTION page 5  
1.5 Support service professionals are using LIU.

<sup>91</sup> The majority of registered users fall out-with age group targeted by the project; the project is targeting people who are over 50. Again this could be indicative of working health professionals using the site or it could just reflect the demographics of web users. For January 2015 more than 63% of the registered users were below 50. By August 2015 this had fallen slightly but there were still more than 60% of registered users below the target age of 50 plus.

name of the project itself, i.e. over 80% of organic searches are done using the key phrase, 'Living It Up' (Alexa, October 2015). We would speculate (although we can't be certain) that users with long-term health conditions and carers are more likely to use a search term related to their own needs rather than type in the name of a project. We would suspect that healthcare professionals are more likely to be aware of the LiU project than members of the public (even if they do have long-term health conditions). But significant marketing and LiU local activity via health and care partnerships would increase personal introductions.

## 5.8 LiU Traffic growth

Despite the quality of the content on the site and the additional marketing in the second half of the year, traffic to the LIU website did not grow consistently across the year. There were some months where traffic increased markedly as a result of social media marketing (September, October and November 2015). However, it fell back to previous levels in the following months once the social media marketing stopped. This was a deliberate experiment to test approaches.

Between January 31st 2015 to January 31st 2016 there were many peaks when new articles were added and marketed. However, as the graph below shows, across the year that did not in itself directly result in increasing page views each month. From January 2015 to January 2016 there were 516,573 page views.

Image 1. The image below shows the trend for LIU users between January 2105 to January 2016.

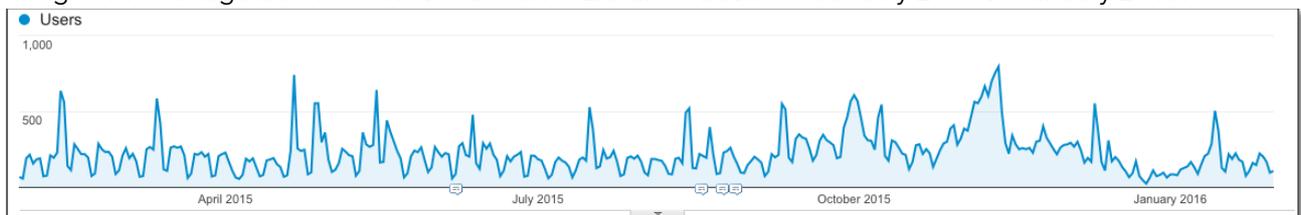
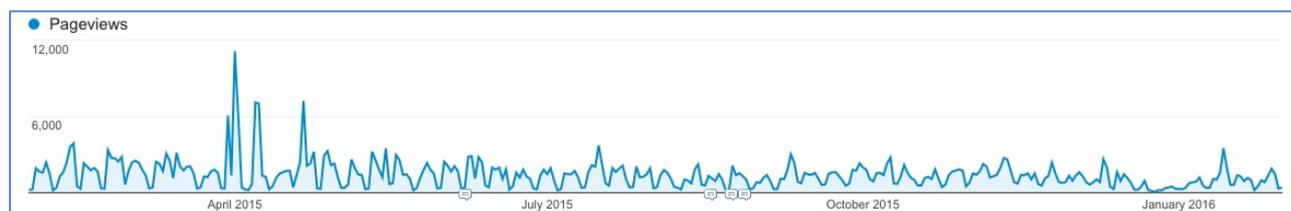


Image 1.1 The image below shows the trend for LIU sessions between January 2105 to January 2016



Between January 31st 2015 to January 31st 2016 there were many peaks when new articles were added and marketed. However, as the graph below shows, across the year that did not in itself directly result in increasing page views each month. From January 2015 thru January 2016 there were 516,573 page views.

Image 1.3 The image below shows page views for LIU for January 31st 2015 thru January 31st 2016



Further supporting evidence for the above conclusion is outlined in Appendix E.

### 5.9 What the data can't tell us (data supplied until 31st Jan)

Looking at the LIU website traffic alone we cannot fully answer the question of whether people are better connected to their support networks or not. It is not clear that the website, social media and interactive tools<sup>92</sup> are helping the target group to engage online. Looking at the LiU Twitter feed and the LiU Facebook page they appear to be mostly used as 'broadcast' channels - with very little interaction and little sense of LIU being the centre of an active community.

We can see from the statistics that 'experience guides' are being regularly added to the site; however, the statistics on their own do not tell us enough about who is adding these guides. Looking at the website, appears to show that a high number of service workers/organisations, not just individuals are adding site content. Although people with LTC are featured in the guides they are not always the people creating and adding the content. It could be suggested that control of content, control of creation of that content and control of managing that content would be more effective in empowering individuals to take more control of their lives.

The raw numbers don't tell us if those participants directly or indirectly involved in content creation are feeling empowered or whether their confidence increased. Further research is required to capture that information. For example, by surveying those who have been involved in content creation.

The visitor statistics themselves do not tell us if the website content, online services and interactions are strengthening links between digital interventions and health and wellbeing. Additional research - ideally involving the participation of those using the site is required. The diary exercise has been an effective tool to discover whether or not active users with long-term conditions are becoming more involved in managing their own health. The web statistics have shown that the content is appropriate to meeting this goal.

<sup>92</sup> We have statistics related to how many people used the tools but no information related to their impact.

## 5.10 Online Tool Use

Statistics related to the number people using online tools was available, however, the resulting user data gathered from their use was not available (or not collected). For that reason, it's difficult to draw any conclusion about the effectiveness of their use. Further research is required, for example, those who used the tools could be surveyed to determine their impact.

Table 1.7 The tables are drawn from data provided in the LIU Management report for January 2016 and show user engagement with the tools on the LIU website.

	Shine quiz completed	Community Challenge	Activity log	Digital Postcard	Experience Guide	Smartcare Diary and PHF	Get active	Smart care falls assist
Numbers who used the tool	1486	150	19	362.5	63	N/A	N/A	1602
Target for number of users	1075	187	180	332	100	325	200	1750

### What is positive about LiU's data in terms of preventative care and wellbeing?

As outlined above, analysis of visitor statistics shows that the website has high quality relevant content and that it is being used by health professionals, carers and those with long-term conditions.

The tools on the website are being used by visitors (i.e. most targets are met for their use) and as such - if they are effectively designed, there is evidence that there is great potential for increased wellbeing and self-management/preventative care.

The growing database of users and newsletter subscribers is a huge resource that should help guide the future direction of the website. As of January 2015, 21,930 LIU users were registered.

### **5.11 Where are all the improvement areas for LiU**

If further investigation finds that the LIU site is mainly being used by health professionals, that suggests that there is still a huge opportunity to directly capture individuals who are part of LIU's target group, i.e. over 50 and have LTC.

It might be useful - in relation to developing the current online tools - to do further research into the degree of change, if any, that was related to carrying out the offline diary exercise. For example, if it is discovered that some of the change shown in the research was down to a 'diary effect' (i.e. filling in the diary was one of the things that led to behaviour change), it might be possible to further design this effect into existing online tools, such as the smart care diaries - or new tools designed for the purpose.

### **5.12 An accessibility audit of the Living It Up website**

As people get older they are more likely to have multiple impairments. For example, most people become aware over time that their eyesight and hearing starts to deteriorate<sup>93</sup>.

The LiU website target group is people over 50 with long-term health conditions. Therefore, it is important that websites are accessible to people with impairments. This section of the report assesses the accessibility of the LIU website.

### **5.13 Standards and definitions**

For the purposes of this report we are referencing the LiU tender document, the UK government's definition of website accessibility<sup>94</sup> and the Worldwide Web Consortium's Website Accessibility Guidelines (WCAG 2)2 up to Priority 2.

In relation to the project tender document, accessibility is mentioned in the following context: "It also aimed to provide an enhanced and personalised experience, save time, be affordable, be easy to operate and understand, and be accessible to users via familiar technology."<sup>95</sup>

The UK government defines accessibility in the following way. "Web accessibility is the practice of making website content available to all users, particularly those with disabilities, including visual, auditory, physical, speech, cognitive, and neurological disabilities. It includes making a website as accessible as possible regardless of browsing technology, such as for people with text-only web browsers and old browser versions."

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<sup>93</sup> BARNETT, K., et al., 2012. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet*, 380(9836), pp. 37-43.

<sup>94</sup> THE UK GOVERNMENT, 2016. *Blog, Government Digital Service*. UK government and accessibility. [online] London: The UK Government. Available from: <https://gds.blog.gov.uk/accessibility/> [Accessed March 2016].

<sup>95</sup> SCOTT, R., 2015. *NHS 24 - LIU Evaluation Tender V0 2*. Glasgow: NHS24. Page 5.

The WCAG guidelines are regarded as the standard guideline for checking the accessibility of websites. Priority 2 is the minimum level recommended by the UK Government<sup>96</sup>.

It should also be noted that the UK Equality Act 2010<sup>97</sup> makes it illegal to discriminate against disabled people. When content or functionality cannot be accessed an alternative way to access that content or functionality must be provided.

### **What can the website access audit tell us (audited 31st Jan 2016)**

It is clear that the issue of accessibility was considered when developing the site and that the site will be accessible (in a technical sense) to most visitors. The site demonstrates good practice in a number of areas:

- Text can be resized without causing layout or readability issues.
- Headings are used appropriately to give structure to on-page content and content is 'marked up' appropriately, i.e. HTML tags are used to indicate which pieces of text are headings, paragraphs, lists and so on. This is important to people using access technologies such as screen readers.
- Skip links are available to allow people using screen readers to jump to important areas of the page.
- Forms still work when JavaScript is not available.
- The site is largely keyboard accessible.
- The site works on other platforms such as tablets and mobiles.

### **5.14 Accessibility of Living it Up for those with visual and cognitive impairment**

As at 31<sup>st</sup> January 2016 the LiU website currently fails at Level 1, and Level 2 (also called A and AA) of the World Wide Web Consortium's Accessibility Guidelines version 2 (WCAG 2).<sup>98</sup> Although the site will be technically accessible to the majority of visitors it fails to meet the accessibility criteria as measured by the checkpoints of WCAG 2 Level 2. Consequently, it also falls short of the UK government guidelines and for some users it will not be, '... easy to operate and understand, and be accessible to users via familiar technology' as outlined in the vision for the LIU website.

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<sup>96</sup> THE UK GOVERNMENT, 2014. *Accessibility. How to make services that everyone can use*. [online]. London: The UK Government. Available from: <https://www.gov.uk/service-manual/user-centred-design/accessibility> [Accessed February 2016].

<sup>97</sup> *Equality Act (UK) 2010* c.15. Available from: <http://www.legislation.gov.uk/ukpga/2010/15/contents> [Accessed March 2016]

<sup>98</sup> WORLD WIDE WEB CONSORTIUM, 2008. *Web Content Accessibility Guidelines*. World Wide Web Consortium. [online]. Available from: <https://www.w3.org/TR/WCAG20/> [Accessed March 2016].

The website also has usability issues (poor usability is itself an access issue) that could make accessing the content difficult for both disabled and non-disabled people: the content is poorly organised, the navigation is inconsistent across the different sections and it is unclear how some functionality should work (for example, the ALISS Google maps). It is worth noting here that the site is now currently undergoing a consolidation exercise to address some of these known issues.

It is likely that the usability and accessibility issues will have had an impact on those who visited the site. Where the diary exercise showed a positive outcome from using the site (i.e. those with LTC felt less lonely and became more computer literate), we can speculate that that impact would have been even more significant if the site had been fully accessible and easier to use<sup>99</sup>. Equally, where there was not a discernible positive outcome - it is possible that that could be down to issues with participants experiencing difficulties using the site rather than being solely related to the quality of the experience, the content and tools themselves.

The accessibility and usability issues could be a contributing factor in relation to the lack of traffic growth to the website in the year covered in this report<sup>100</sup>. Although it is clear from the statistical analysis that the site has a lot of good and relevant content, if visitors are not finding it when they are on the site they are unlikely to come back, to tell their friends about the site or to point to it from their own websites or blogs. For example, a case study carried out in 2007 showed that accessibility improvements by the Legal & General Group doubled visitor numbers increased natural search traffic by 50%.<sup>101</sup>

In terms of behaviour change, if users, carers or practitioners, all of whom may have impairments, are unable to access the content, or find the site difficult to use, then we can speculate that the opportunity for behaviour change is reduced.

Improving access to the website will increase the number of visitors to the site. A larger audience will increase the potential for interventions and opportunities to access services. Increasing the accessibility and usability of the site will also make the interventions more effective.<sup>29</sup>

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<sup>99</sup> BIAS, R. G. and MAYHEW, D. J., 2005. *Cost-justifying Usability: An Update for an Internet Age*. Burlington: Morgan Kaufman.

<sup>100</sup> COMMUNIS LTD SEO and Accessibility Overlap [Online] Available from: <http://tinyurl.com/qrcns9> [REFERENCE TO BE AMMENDED]

<sup>101</sup> WORLD WIDE WEB CONSORTIUM, 2009. *Case Study of Accessibility Benefits: Legal & General Group (L&G)*. [online]. World Wide Web Consortium. Available from: <http://tinyurl.com/gs2hjf> [Accessed March 2016]

### 5.15 Examples of issues that should be addressed to ensure the site is accessible to people with a range of impairments

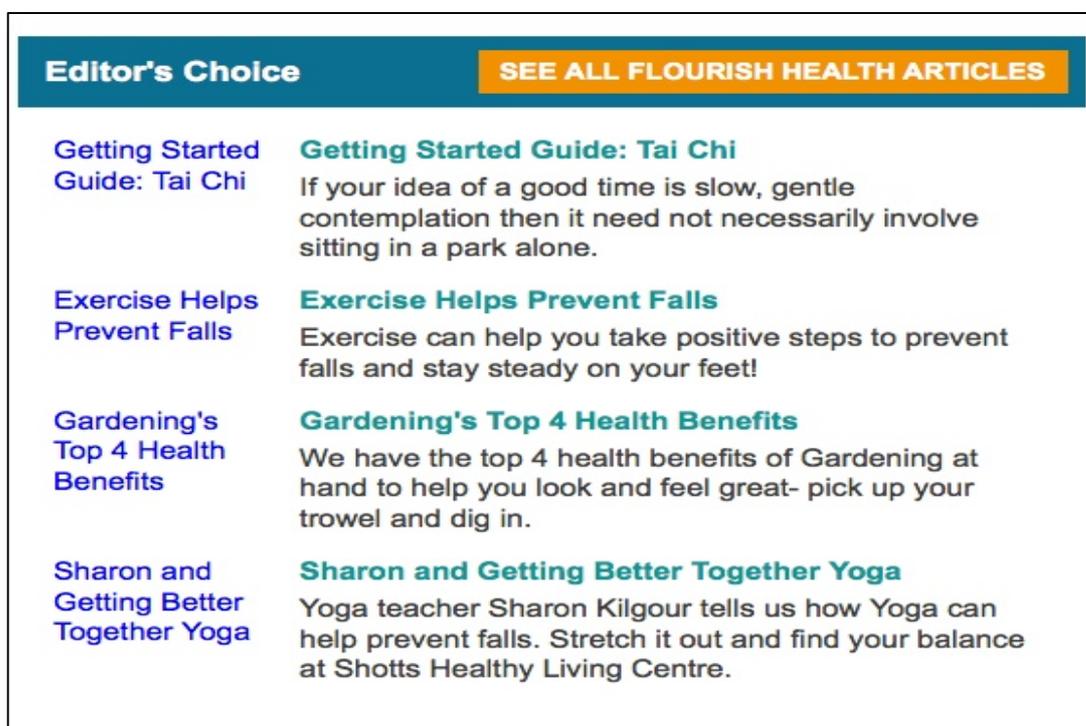
The following are brief notes related to examples of the failed WCAG 2 checkpoints found during the audit. Failed checkpoints imply that the site does not meet UK government minimum standards or necessarily be 'accessible to users via familiar technology' as required by the LIU tender document.

More detailed notes related to these issues and other issues found (not covered in this document) can be found in the Appendix E - where a checkpoint table of the failed W3C guidelines is provided.

### 5.16 Appropriate text alternatives should be provided for non-text content

Although the site passes the automated test for this checkpoint (all image tags have alt attributes) not all of the descriptive labels used are appropriate or useful in practice. For example, labels should be removed when they duplicate nearby text, otherwise screen reader users will read the same text twice (see the text in the example image below). This is a recurring problem on the site, e.g. on the home page the image related to the getting started guide has the same text as the heading next to it.

Image 1.4. Screen grab shows how Living it Up's text is same as headings as at 31.1.16



### Accessibility of Living it Up's search function

The search form on the home page would be confusing for people using screen readers, as the image used for the submit button has no text label. When images are turned off, the search form has no submit button - so essentially the search form will not be usable for some visitors.

### Accessibility of Living it Up's content, especially video

The content of the 'Get inspired' videos will not be accessible to screen reader users. Ideally there should be transcripts or some alternative way to access this content. When images are turned off there is just a blank area on the page; there are no visible links to the videos or to alternative content such as a transcript of the video.

Image 1.5. Screen grab of Living it Up shows how videos have no labels or captions



### 5.17 Living it Up's navigation scheme

One of the main issues is the inconsistent navigation across the site. For example, the area of the page that is 'traditionally' reserved for the main navigation does not always contain the same set of links. Some pages have breadcrumbs navigation, which is good because it provides context, however, some other sections do not.

The links above the navigation bar (which in itself is in an unconventional area to situate navigation and is, therefore, a usability issue) contain the same links as the boxes on the

content area of the page. It is not clear what the difference is between the link on the main navigation bar to, 'Your Area' and the box with the link to 'What's available to you locally'. Anything that makes a visitor think 'what or why' i.e. why are there two links to the same thing, what is the difference between these two similar links, is a usability problem.

Some pages have no navigation bar and no breadcrumbs trail, e.g. the registration page, the 'Discover' page and the digital postcards page. On other pages the navigation links do not match up with those on the home page.

For example, the home page navigation bar:

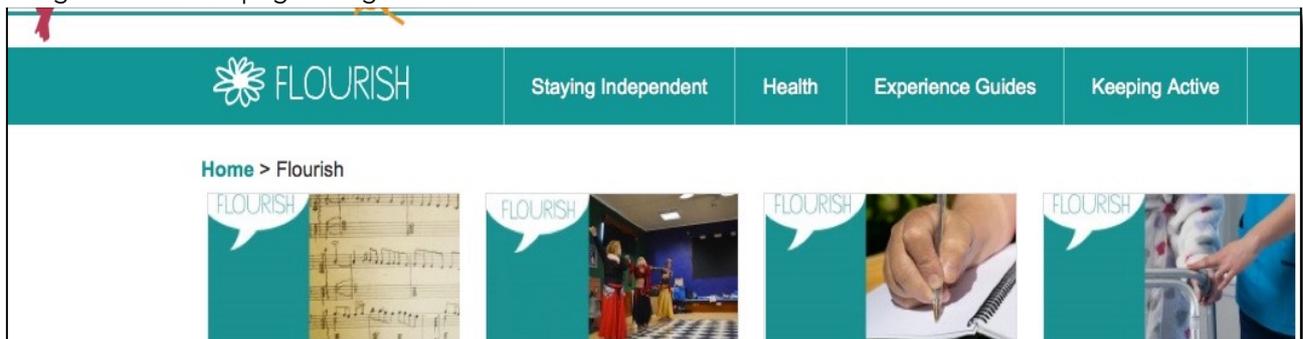


Image 1.6 Home page navigation bar.

### Home page navigation bar 1

Is different from the 'Flourish' navigation bar:

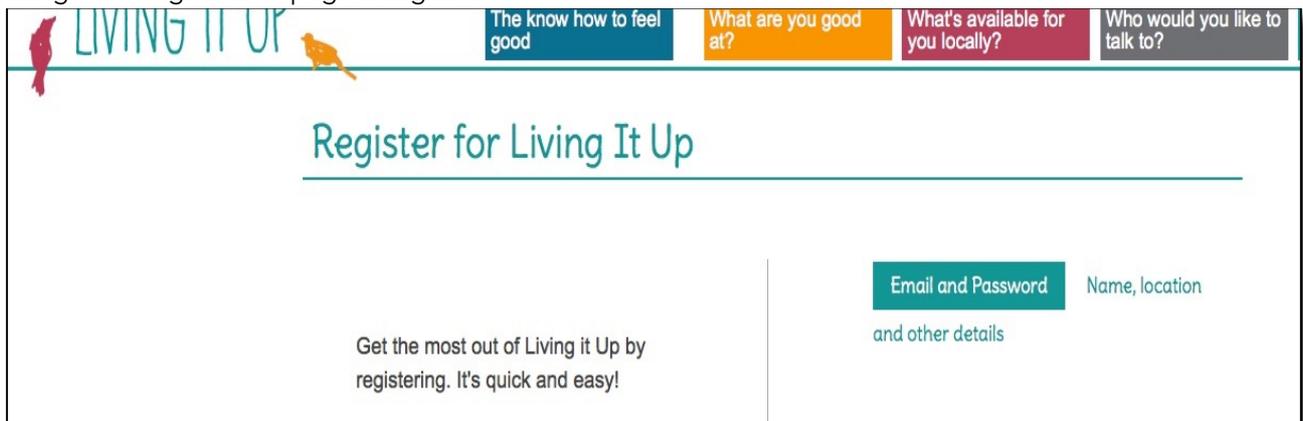
Image 1.7 Flourish page navigation bar.



### Flourish section navigation area 1

Which is different from the registration page navigation:

Image 1.8 Registration page navigation bar.



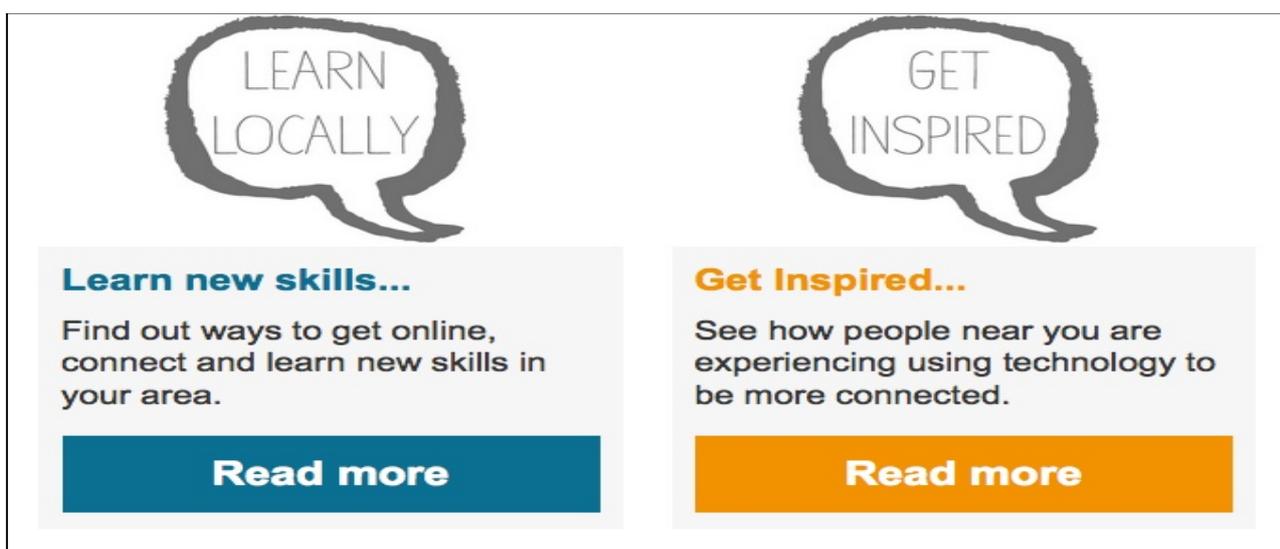
### Registration page navigation area 1

The justification for this can be understood, i.e. that this is regarded as the sub-navigation and not the main navigation. However, as it is located in a place where users would expect to see the main site navigation, this approach lowers usability as well as lowering accessibility for users who need consistency. For example, people with a cognitive impairment or people using access technologies such as screen readers.

### There are text links that do no make sense when read out of context

There are many instances of links that would not make sense if they were read out of context, for example the 'About us' page is littered with links that just say, 'More' and the 'Connect' section has many, 'read more' links.

Image 1.9 Read more links.



## Read more links 1

A person using a screen reader would hear these links but not know where they would go if they clicked them. It is common for people using screen readers to summarise all of the links on a page into a single list; in this case that list would consist of many, 'read more' links, which is clearly a problem for navigating around the site.

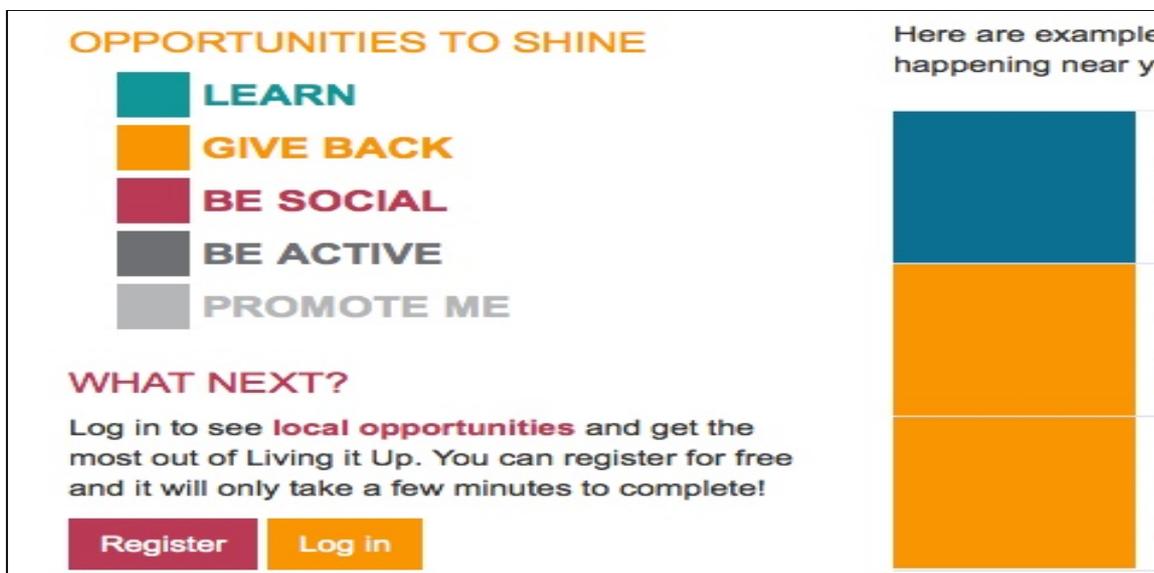
## 5.18 Use of jargon on the website

Jargon is used throughout the site. For example, 'co-designing', 'online self-management hub', 'Person Held File'. Whether this is appropriate depends on the target audience; i.e. for a professional health support audience this jargon may well be relevant and useful, however, if the main audience is expected to be members of the public and specifically older people with health issues, this language may not be appropriate.

## Links that are not links

On the 'Find Opportunities' page there is a list of 'Opportunities to shine' that look like they are clickable, but when I clicked them they did not appear to do anything. This was the same for the three coloured squares on the right of the page - and for the three 'thumbs up' icons. I clicked them all but nothing happened.

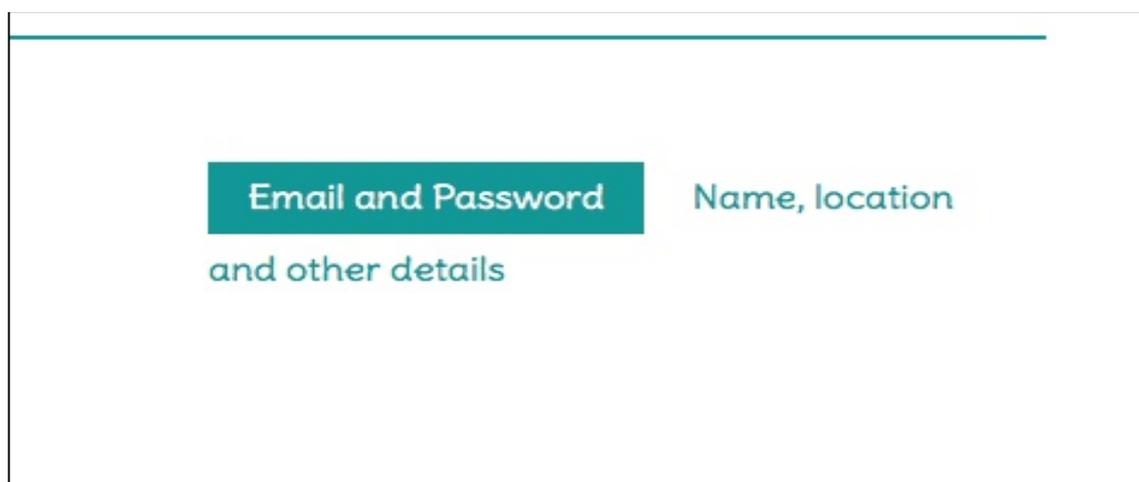
Image 2. Coloured boxes that are not clickable.



## Coloured boxes that are not clickable 1

The registration page is confusing; there are words on the right-hand side of the page (email, password, Name, location and other details) which look like they may be part of the registration form but are not; they seem to be for displaying registered users details - but for someone who is not registered they are superfluous and confusing.

Image 2.1 Email and password form.



### 5.19 Errors on the site

At the time of the test there were errors in the functionality of the site. For example, filling in the user registration form led to a page with an error message; the error message says that the page does not exist. The first page that appears after successfully logging in to the site showed a message asking the user to register; which is clearly a bit confusing.

### Google Maps

It is not immediately clear how the set of small Google maps on the 'Your area' page was supposed to work and there was no explanation. The way the experience guides worked felt less than ideal, i.e. it was not clear that visitors had to use the pull-down menus to access the content. After accessing the content via the pull-down menus; the way the content was presented seemed confusing.

It felt as if clicking the link should take the user to the related content; however, it subsequently became clear that the small amount of text under the question was the content related to that question. Sometimes there was no content in the areas chosen via the pull-down menu. Having got to the content you need to click the back button to choose another area; ideally, if the pull-down menus are to be used - they should remain in the same place on each page.

### 5.20 How can the accessibility of the LIU website be improved

The following points will have a large impact on improving the accessibility and usability of the LIU website.

- The site structure and navigation should be updated so that it is consistent across the entire site. Thus, while we are aware that there are technical reasons for the current structure, i.e. the LiU website has been developed by pulling together content from different sites and multiple sources, if they can be 'sewn' together in a more transparent and consistent way the usability of the site will be improved.
- Update all of the 'more' and 'read more' links so that the link text contains information related to the pages being linked to.
- Review the text labels that have been added to images and non-text elements on the site and remove any that are inappropriate. Add transcripts for the videos or find a way to make the content of the videos accessible to people with visual impairments.
- Carry out usability testing of the LiU website. Informal usability tests involving a small user group will provide valuable information about issues on the site and how it could be improved, both in terms of accessibility and usability.

Improving the usability and accessibility of the LiU website will have a big impact on the value of the site for users with long-term conditions. The easier the site is to use the more likely people are to use it and get value from it.

### **5.21 What the usability audit does not tell us**

Although this audit tells us if the content on the site is accessible or not, it does not tell us how effective that content is, who is using the website and whether using the content and tools on the website will lead to behaviour change.

## 6.0 Social Return On Investment

### **6.1.1 How this section is structured**

How a social return on investment (SROI) has been calculated for Living it Up is detailed in this section as well as a social return on investment figure and details. It describes the assumptions made, what material elements have been included and what elements of LiU's services have not.

This Chapter is further supported by Appendix F that details the specific calculations within an Excel Spreadsheet. This spreadsheet forms the 'Impact Map' that is referred to within this Chapter and outlines the exacting calculations that have formed the SROI figure.

### **6.1.2 About SROI**

The nature of Social Return on Investment (SROI) is to explore in as robust a way as possible what returns for stakeholders might be expected from investment in an intervention. The SROI analysis reported below however has identified a number of uncertainties in assumptions and estimates that have had to be made which reduce the level of robustness of this analysis. This reflects the developmental stage that LiU is in.

### **6.1.3 Description of SROI method**

SROI is a principles-based approach to measuring social value for a range of stakeholders. The 7 principles are:

- Involve stakeholders
- Understand outcomes from the perspective of stakeholders
- Value what matters
- Only include what is material
- Avoid over claiming
- Be transparent
- Verify the account

The main output from this work is an impact map, which shows the theory of change from the perspective of each material stakeholder, for the 2015-2016 financial year.

The map uses measurement of achievement of outcomes derived from the evaluation information collected through active users and carer diaries and telephone interviews.

These outcomes are then given a value using financial proxies. The impact shows the value derived for each stakeholder, as well as an overall ratio of return from the programme's activities. Given the extent of assumptions and judgements needed to create the impact map, there has also been a sensitivity analysis conducted and so the SROI ratio reported on here is reported as a range, rather than one single figure.

The impact map created for LiU is in Appendix F, together with the detailed assumptions that have been used in the analysis.

#### **6.1.4 Included stakeholders**

The stakeholders for whom there has been an engagement process, for whom data has been collected and outcomes have been verified and whose outcomes have been valued are:

- LiU 'active users' i.e. people living with long-term conditions for more than 12 months who are registered to use digital tools and contribute content to LiU and who use LiU more than twice per month
- Family carers of people with long-term conditions, who also have long-term conditions themselves.

There are also stakeholders who have been identified as material, based on the engagement process with LiU users and carers and, where the data collected from services users can be used to infer an impact on these stakeholders, it has been done so. These stakeholders however have not been directly engaged with during the evaluation. These are:

- Community-based organisations
- NHS primary care services

#### **6.1.5 Excluded stakeholders**

There are many stakeholders who are likely to experience a material impact as a result of LiU, but for whom there is currently no direct evidence to be able to include them in the impact map. These are:

- Members of LiU, who sign up for and receive a monthly newsletter (approximately 19,000 at March 2016), the impact for whom is currently not recorded;
- Partners from care and health sectors who have benefited via a corporate context; and,

- Local health and social care practitioners working within the local partnership structure for LiU, whose survey results are still in the collection phase, and so could not be included in the impact map.

There are also potential stakeholder groups for whom we have insufficient evidence to make a judgment as to whether there might be any material impact or not. Casual users of LiU who do not register are an example of this stakeholder group. The assessment is therefore the 'minimum' that we can evidence.

#### **6.1.6 Outcomes for stakeholders**

One of the challenges in engaging with stakeholder groups is to create a theory of change in relation to the activity, to chart the chain of cause and effect, and to identify what are short, medium and long term outcomes that might be connected in what SROI calls a 'chain of events' (similar to a logic model). The overall theory of change in relation to LiU is discussed elsewhere in this report, but in an SROI analysis, the principle of not over-claiming requires identifying the right outcome to measure and value. This has been taken to mean identifying the direct current impact on e.g. LiU active users, as a result of their use of LiU, and not to assume longer term benefits that might be expected from research to accrue to users but have not yet been evidenced.

The diary analysis was used to identify where significant differences are reported between the control and the intervention group. These have then been compared to the reports made during the telephone interviews, to find the most appropriate way to represent outcomes for different stakeholders.

Thus the SROI analysis has been conducted on the sample of control and intervention groups and what they have said.

Table 2.0 Illustrates evaluation evidence collected supports the following outcomes being achieved as a result of LiU.

Table 2.0 details of outcomes and evidence for said outcomes.

<b>Stakeholder group</b>	<b>Outcome</b>	<b>Evidence used</b>
<b>LiU active users</b>	1. Being more able to manage one's own physical health	<p>1. People in the intervention group report that they had joined groups and activities as a direct result of LiU (or taking their own responsibility for their LTC).</p> <p>2. The intervention group report a reduction in the frequency with which they had contacted a care professional/social care service when compared to the control group</p>
	2. People are more connected in their community and doing activities and people are less lonely	<p>1. Higher number in the intervention group reporting they were volunteering in their community</p> <p>2. Higher number in the intervention group reporting they were more connected with their family compared to the control group</p>
	3. More people with LTCs are motivated to access online information and less likely to contact a professional in order to make themselves feel better	<p>1. Higher number of people in the intervention group reporting that they used online resources in preference to professional contacts</p> <p>2. Less people in the intervention group saying they had contacted a care professional/social care service compared to the control group</p> <p>3. Less people in the intervention group saying they had contacted a community/volunteering for a service compared to the control group</p>
<b>Family carers</b>	1. Increased sense of personal control and self-efficacy	<p>1. Higher levels in the intervention group reporting they had tried a new caring technique or tried something new with the person they cared for compared to the control group</p> <p>2. Significant increase in the intervention group reporting they understand the nature and causes of the health condition of the person they cared for compared to the control group</p>

<b>Community-based organisations</b>	1. Recruitment of a greater number of volunteers	1. The increased number of people volunteering in their community in the intervention group
<b>NHS Primary care services</b>	1. Reduce demand through self-management activity undertaken by patients as a greater number of patients are activated and motivated to manage their conditions themselves	1. People in the intervention group report they had joined groups and activities as a result of LiU or taking their own responsibility for their LTC 2. Significant reduction in the intervention group saying they had contacted a care professional/social care service compared to the control group

Thus outcomes for community-based organisations and NHS Primary care services have therefore been inferred from the reports from LiU users.

### 6.1.7 Financial proxies

SROI is different from other monetisation methods in taking valuations from different stakeholder groups and adding them together to calculate value. Value is perceived differently by different stakeholders, but SROI principles have been developed to ensure we understand as much of the impact as possible, rather than take the perspective of one stakeholder only.

In a full SROI evaluation analysis, information about how some stakeholder groups value outcomes would be secured directly from engaging with that stakeholder group. This has not been possible in this evaluation, except through the telephone interviews with LiU active users. In any case, the small numbers involved in the interviews would be likely, based on SROI experience to date, to lead to very high valuations that would skew the result.

As SROI has developed over the last 10 years, more commonality in valuing some outcomes has been created and there are numerous sources of financial proxies.<sup>102</sup> There are a range of methods based on existing economic evaluation approaches which are recommended for use in developing financial proxies, some of which are relevant to particular stakeholders, and some of which have been used to evaluate the LiU outcomes:

<sup>102</sup> GLOBAL VALUE EXCHANGE, 2015. *Discover your social value*. [online]. Glasgow: Social value UK. Available from: [www.globalvaluexchange.org](http://www.globalvaluexchange.org) [Accessed February 2016].

- Changes to unit or marginal costs (whether potential or actual cash savings)
- Changes to income
- Revealed preference i.e. the preferences of individuals can be revealed by the market price for an equivalent outcome
- Hedonic pricing, which is a type of revealed preference proxy i.e. valuing the change in the utility of something by seeing how the valuation of it changes as its characteristics change. (This approach has mainly been used to value changes in environmental amenity by seeing how they affect house prices)
- Stated preference i.e. directly asking people to give their valuations through surveys of large samples
- Contingent valuation, which is a type of stated preference proxy i.e. directly asking people to give an estimate of their willingness to pay to have something or avoid or accept something
- Travel cost method, which is a type of stated preference proxy, i.e. directly asking people to state the time and travel costs that they are willing to incur in order to have something, which can represent the value of access to something.

Data like the British Household Panel Survey (BHPS) can be used to estimate the impact that a non-market good or outcome has on a dimension of Subjective Well-Being (SWB), such as improved life satisfaction. The BHPS can then be used to look at the impact that extra income has on SWB. From a comparison of these two estimates, we can then calculate the equivalent value of the particular non-market good i.e. the amount of extra income that would be required to produce the equivalent impact on life satisfaction.

So for example, having a skin condition or allergy can reduce life satisfaction. The SWB approach calculates that you would need an extra £895 in income per year to return you to the same level of life satisfaction you would have if you did not suffer from the condition. This figure could be used to value a treatment that removed the skin condition or allergy, from the perspective of the patient.<sup>103</sup>

In this study, the SWB approach has been used to value the increased self-management of long-term health conditions experienced by LiU users. Further details can be found in Appendix F.

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<sup>103</sup> FUJIWARA, D. and DOLAN, P., 2014. *Valuing Mental Health: how a subjective wellbeing approach can show just how much it matters*. [online]. London: UK Council for Psychotherapy. Available from: [http://media.wix.com/ugd/9ccf1d\\_b3cfc47c5b2043ec92b32f558d15d97f.pdf](http://media.wix.com/ugd/9ccf1d_b3cfc47c5b2043ec92b32f558d15d97f.pdf) [Accessed February 2016].

### 6.1.8 Findings and sensitivity analysis

The table below provides a brief overview of other SROI reports for organisations making health and well-being impacts:

Table 2.1 Social Return on Investment figures in UK for public services in UK

Organisation	Programme	Outcomes	SROI Figure
<b>Home Office: National Treatment Agency for Substance Misuse</b>	Collaborative study by the Home Office, Department of Health and the National Treatment Agency for Substance Misuse to develop a Value for Money model and applying it nationally in the context of crime prevention and health improvement benefits of treatment and recovery in regard to substance misuse.	It was estimated that for every £1m taken out of the adult drug treatment system there would be a cost to society of £1.8m due to drug-related crimes.	<b>1:1.80</b>  For every £1 spent there is a social return of £1.80.
<b>Health Innovation Network UK</b>	The objective of the three peer support groups was to provide support for people with dementia through providing a facilitated environment for people to meet and socialise, with a variety of dementia appropriate activities to engage group members.	By providing peer support groups for individuals in south London a positive social value for people with dementia, carers and volunteers that is greater than the cost of investment.	<b>1:1.17</b>  For every £1 spent there is a social return of £1.17.
<b>Royal Voluntary Service (WVRS) and Leicester Infirmary</b>	WRVS asked Frontier to carry out a Social Return On Investment (SROI) evaluation of its services for older people. In Leicester Royal Infirmary the study covered Meet and Greet, Retail, Community Transport Scheme, Buggies and Clinic Volunteers. Meet and Greet is where volunteers help users find their way around the hospital. Retail comprises four shops within the hospital run by volunteers. The Buggies service provides transport support within the hospital for people with mobility difficulties. Clinic volunteers provide support for paid clinic staff in places like eye and fracture clinics.	The key finding in the report was that local authorities, not just the health service stand to make significant savings from aspects of our work.	<b>1:1.98</b>  For every £1 spent there is a social return of £1.98.

## 6.2 A SROI figure for Living it Up

The impact map for Living it Up determines that the range of returns to included stakeholders from the LiU investment is currently up to £2.80 returned for every £1 invested in Living it Up. The most likely return being within a positive range i.e. more than £1.37 and up to £2.80 returned for every £1.00 invested. See Appendix F for how this range has been calculated.

The range comes from varying the key assumptions that have been made in order to generate the ratio which have been affected by:

- Whether the investment figure for LiU should include development costs or not
- Attribution levels, i.e. isolating the contribution of LiU from a range of other factors
- Duration of outcomes into the future
- The financial proxies used to value outcomes.

How far one can scale up from the findings in this evaluation study to the cohort of LiU users in general is a consideration point, but the finding does suggest that LiU even at this stage in its development, is potentially starting to generate a return on its investment. As numbers of active users increase and development costs as a proportion of the overall budget start to reduce, ROI would increase.

### 6.2.1 Limitations on the SROI analysis

There are however a number of limitations and weaknesses that have been identified in this analysis.

1. The questions used in Hibbard's theory of patient activation and translated into the diary questions are not questions that would normally form the most illuminating way to understand change in an SROI study.

The more usual way to proceed in an SROI study would be to mount a process of engagement with people who are part of the stakeholder group (in this case, primarily LiU users) and ask them to discuss and agree their theory of change, however this was not part of the brief. In the course of engagement, one would normally find unintended positive and negative outcomes. Only then would one mount a data collection exercise to establish what percentage of the stakeholder group experienced the outcomes. It is likely that outcomes are being missed.

2. There are stakeholders missing due to lack of data, so this analysis is likely to underestimate the value created by LiU.
3. Valuations have been based on research, with limited verification by LiU users. The final SROI principle is to verify the account, and it is recommended that this is done with the key stakeholders.
4. The diary format has yielded limited information on behaviour-based (or objective) indicators of outcomes e.g. the extent of reductions in medication, the amount of additional time spent out of the house in social/community activity etc. Some of this was gleaned from the telephone interviews, but was not systematic enough to be certain about the quantities used in the impact map.

## 7.0 CONCLUSIONS

### LIVING IT UP ENABLES THE FOLLOWING BEHAVIOUR CHANGE IMPACTS TO TAKE PLACE:

- Greater levels of adherence to preventative care and health routines conducted at home or in the community, either individually, at an aggregated level or with partner support;
- Lower self-reported levels of use of care services and higher levels of volunteering in community and peer groups than non-users of LiU;
- Improved level of community, social and physical mobility;
- More appropriate food selection and diet choices;
- Use feasible and achievable goal setting to overcome changes in symptoms and periods of illness or difficulty when managing their long-term condition: 'Bethany (IR1), experiencing chronic pain and rheumatoid arthritis with hip, knee and finger joint replacements: *'I've become afraid of falling [since I fell]. But this year, I've decided that I need to get back thinking positively that 'I will be fine'. I didn't go to one of my [social] groups and I felt bad. I won't let that happen again. I won't let fear take a grip any longer'*;
- More likelihood of having greater levels of resilience and coping management strategies for care of their LTC following change or social or environmental stressors;
- More accurate detection of symptom change and in some instances, awareness of self-diagnoses, data analysis and decision-making (e.g. caring routines, testing blood glucose and adjusting lifestyles if diabetic etc.);
- Instigation of more proactive communication with physicians and carers, enabling active users to become 'expert patients' and demand differing ways to connect with NHS services that avoid waste of existing care and health resources; and,
- Modification of his or her living lifestyle and social and/or work environments to support better management of and, reduction in symptoms of, their LTC or when caring for another person.

### LIVING IT UP'S SOCIAL RETURN ON INVESTMENT FOR EVERY GBP SPENT IS: 1: 1.37

### LIVING IT UP'S ACCESSIBILITY FOR THOSE WITH LONG-TERM CONDITIONS AGED OVER 50 IS:

- Overall, good for those who are digitally skilled and fully able
- Is inaccessible to those with impairment or disability without adjustments being made

### 7.1.1 How this section is structured

This section presents a summary of the conclusions from each of the four evaluation elements.

Ahead of reading this Chapter, readers are reminded that the dynamic between Living it Up's (LiU) local innovative initiatives (SmartCare and GetActive), and LiU's online presence, has not been evaluated. This is because participants who opted into the evaluation via the online service were not using either of these two community services.

In addition, readers are also reminded that findings in this cohort study are indicative. This is due to several restrictive factors that affected the scale of the study, including: scope, budget and time.

Conclusions are grouped according to each of the four areas of evaluation enquiry: behaviour change; impact; accessibility; and, Social Return on Investment (SROI) of the LiU evaluation.

At the end of this chapter, additional conclusions are drawn about how Living it Up contributes to health and care policies within Scotland, namely: Scotland's healthcare quality strategy<sup>104</sup>; Improving Health and Wellbeing of People with Long-term Conditions (LTCs) in Scotland<sup>105</sup>; and, Equally Well<sup>106</sup>.

### 7.1.2 General conclusions

Living it Up is a developing user and community-led health and care service that can evidence direct impacts on those that use the online service twice or more a month.

Findings in this report show that:

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<sup>104</sup> THE SCOTTISH GOVERNMENT, 2010. *The Healthcare Quality Strategy for NHSScotland*. [online]. Edinburgh: The Scottish Government. Available from: [www.gov.scot/resource/doc/311667/0098354.pdf](http://www.gov.scot/resource/doc/311667/0098354.pdf) [Accessed March 2016].

<sup>105</sup> THE SCOTTISH GOVERNMENT, 2009. *Improving Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan*. [online]. Edinburgh: The Scottish Government. Available from: [http://www.sehd.scot.nhs.uk/mels/CEL2009\\_23.pdf](http://www.sehd.scot.nhs.uk/mels/CEL2009_23.pdf) [Accessed February 2016].

<sup>106</sup> THE SCOTTISH GOVERNMENT, 2008. *Equally well, report of the ministerial task force on health inequalities*. [online]. Edinburgh: The Scottish Government. Available from: <http://www.gov.scot/resource/doc/229649/0062206.pdf> [Accessed March 2016].

- Active users of LiU self-reported a three times lower instance of needing care services over the study period than the control group and a far higher rate of volunteering in care, peer-group and community care groups.
- As a result of feeling empowered and confident through active use of LiU, patients and carers feel 'activated' and able to instigate, trial or sustain new techniques that may better support their LTC. These trialled techniques include: instigation of healthy food initiatives, exercise and recreation and social connectedness with friends and family. Many more of LiU's active users self-report that they volunteer in their community and have and/or can cope with planned and unplanned health obstacles;
- Active users interact with LiU's online service to inform and generate adjusted self-care and self-management techniques, proactively managing long-term health conditions;
- LiU partners and community members influence the way in which public policies and practices innovate the delivery of health via digital means, responding to the health needs and inequities experienced by those with LTCs and/or carers in Scotland;
- LiU has met the majority of its key performance indicators for the service set within its management and delivery plans for 2015-2016;
- This cohort study has not found evidence that LiU makes measurable difference to reported levels of improvement in well-being in active users which may or, may not be, due to the cohort groups being unable to de-couple the notion of well-being from their physical health separately from their well-being; and,
- That a cohort evaluation approach makes a suitable evaluation model to evaluate LiU in future across behaviour change, SROI and impact. Further, it is augmented when this is supported by an independent review of web analytics using WC3 government standards for digital services.

## 7.2 Conclusions on behaviour change

Indicative findings suggest that LiU's online service can be aligned to a validated behaviour change model the COM-B system (Michie, van Stralen and West 2011)<sup>107</sup>.

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<sup>107</sup> MICHIE, S., VAN STRALEN, M. M. and WEST, R., 2011. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6(42), pp. 1-11.

The COM-B model was used independently in 2006 by the National Institute for Clinical Excellence (NICE) to generate obesity guidance<sup>108</sup> and in 2010 by the English government's tobacco control strategy policy development<sup>109</sup> and is evidenced by The Kings Fund to lead to behaviour change.

See diagram 1. of COM-B Model next.

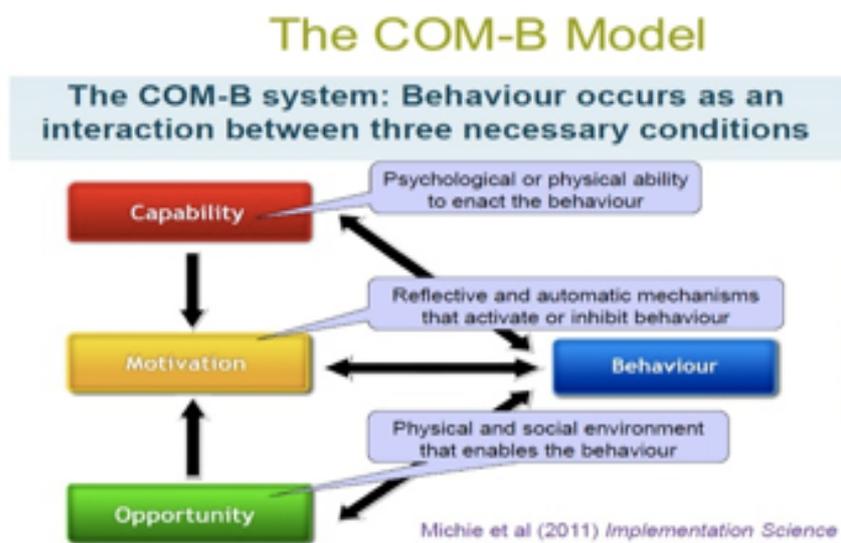


Diagram 1: COM-B theory of behaviour change

In contrast, there is lower instance of trial of new techniques in the control group 'Mary (CU8), Mental health, arthritis, bad back and a carer: "I just live with it and get pain killers for that. There is nothing for arthritis that [doctors] can do."

Behaviours that are either instigated, trialled and/or sustained are:

- Greater levels of adherence to preventative care and health routines conducted at home or in the community, either individually, at an aggregated level or with partner support;
- Lower self-reported levels of use of care and health services;

<sup>108</sup> NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE (NICE), 2006. *Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children*. London: NICE.

<sup>109</sup> NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE (NICE), 2006. *Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children*. London: NICE.

- Improved level of community, social and physical mobility;
- More appropriate food selection and diet choices;
- Feasible and achievable goal setting;
- Higher levels of volunteering and peer group association;
- More resilient coping management strategies for care of their LTC when symptom change. For example when caring duties change, or when holidays interrupt routines and/or times of personal distress and/or stress (such as recovery from falls or admission to hospital);
- More accurate detection of symptom change and in some instances, awareness of self-diagnoses, data analysis and decision-making (e.g. caring routines, testing blood glucose and adjusting lifestyles if diabetic etc.);
- Proactive communication with physicians and care givers will take place, enabling active users to become expert patients and demand differing ways to connect with NHS services that avoid waste of care and health resources; and,
- Modification/s of his or her living lifestyle, social and work environment to support better management of and, reduction in symptoms of their LTC or those of the person they are caring for.

### 7.3 Conclusions on impact

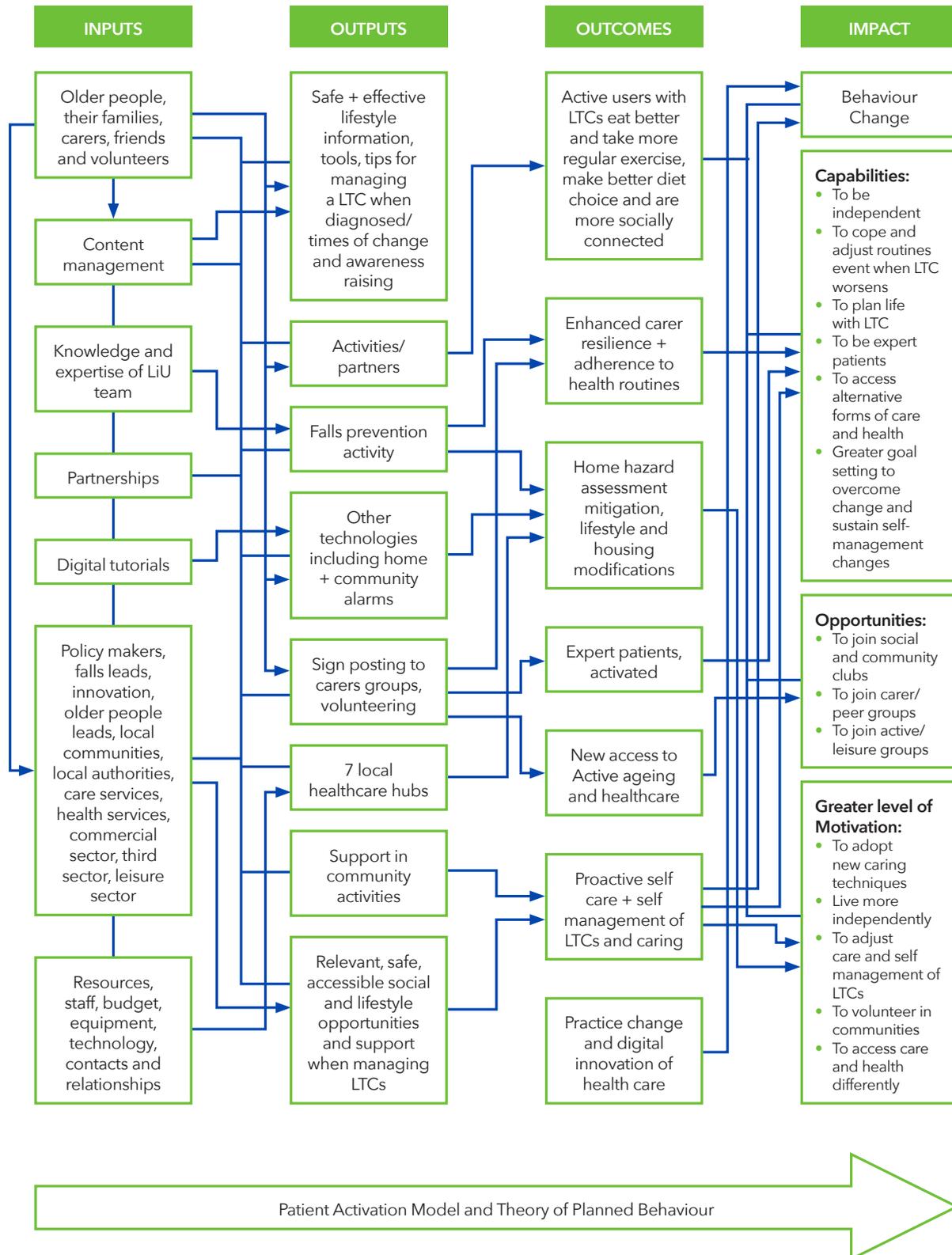
Findings show that there are several areas of impact that are derived by active users of LiU:

- Increased self-management of long-term conditions (e.g. diet adherence, visiting health and care services only when needed);
- Increased levels of self-care via motivation and information to enable them to look after themselves when they can, to be more social and 'to live a life better';
- Goal setting for planning around planned and unplanned obstacles that arise from a LTC or caring duties. This might mean setting up positive social and/or health plans to trial new caring techniques for their own benefit or to benefit the person they are caring for;
- Self-efficacy or self-belief when navigating around unforeseen or planned problems in regards to their symptoms, improving coping strategies at times of diagnosis, new diagnoses of further LTC complications and/or at times of environmental stress;

- Activation in care and health consumption via digital access routes provided by LiU where those digital routes are provided in care and health settings, becoming 'expert patients'; and,
- Volunteering/community work improving social connectedness.

Findings regarding the outcomes and impact generated by LiU's mix of community, regional and national services delivered directly to active users and online settings, are summarised and illustrated in diagram 2. Diagram 2 is a logical diagram. Logical diagrams are used to illustrate the key drivers behind a service and what its outcomes and impacts are using a theory of change.

## Logic Diagram for Findings



## 7.5 Conclusions on accessibility

The accessibility audit for LiU was conducted using data collected up until 31.1.16. Conclusions are drawn based on that end date, though it was understood at that time that LiU is undergoing a consolidation of the site that will be completed and tested by end of April 2016.

At 31.1.16, it was clear that the issue of accessibility had been considered when developing LiU within the vast infrastructure of the NHS and its partners in Scotland. It was also clear that the online service is accessible (in a technical sense) to most active users and browsing visitors. Equally, it is clear that web analytics are regularly reported, analysed and used to improve LiU's early development into a supportive online health and care long-term conditions service.

To this end, LiU demonstrates good practice in terms of accessibility in a number of areas:

- Text can be resized without causing layout or readability issues;
- Headings are used appropriately to give structure to on-page content and content is labelled i.e. HTML tags are used to indicate which pieces of text are headings, paragraphs, lists and so on. This is important to people with impairment who might be using access technologies such as screen readers;
- Skip links are made available to allow active users to use screen readers to jump to important areas of the page they are interested in;
- Forms that active users are invited to complete on LiU still work when other functionality on the service is not available;
- The site is (largely) keyboard accessible; and,
- The site works on other digital platforms such as tablets and mobiles which can increase routes of accessibility for some.

However, at 31.1.16 LiU failed a number of accessibility tests, failing at Level 1 and Level 2 (also called A and AA) of the World Wide Web Consortium's Accessibility Guidelines version 2 (WCAG 2)<sup>110</sup>.

Given that the diary research showed a number of positive outcomes arising for active users who were using LiU, i.e. those with LTCs and carers were more socially and physically

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<sup>110</sup> THE UK GOVERNMENT, 2014. *Accessibility. How to make services that everyone can use*. [online]. London: The UK Government. Available from: <https://www.gov.uk/service-manual/user-centred-design/accessibility> [Accessed February 2016].

mobile and became patient experts for example, it seems logical to assert that changing the way that LiU's content can be navigated and organised could have a positive impact on the benefits and outcomes as well as value arising from LiU in future, if LiU is to be made fully accessible to those with impairment<sup>111</sup>.

In addition, LiU also has a number of usability issues (poor usability is itself an accessibility issue) that could make accessing the content difficult for both disabled and non-disabled people. In addition, some of the content at 31.1.16 is poorly structured and organised, with navigation being inconsistent across different sections. For example, the ALISS Google maps<sup>112</sup> noted in Appendix E.

The statement about how evidence-based analytics improves health and well-being appears in Appendix E.

## 7.6 Conclusions on Social Return on Investment (SROI)

The SROI impact map located in Appendix F shows the theory of change from the perspective of active users canvassed in the cohort study of LiU.

The map uses measurement of achievement of outcomes derived from the evaluation information collected through diaries and telephone interviews. These outcomes are then given a value using financial proxies. The impact shows the value derived for each stakeholder, as well as an overall ratio of return from the programme's activities. Given the extent of assumptions and judgments needed to create the impact map, there has also been a wide-ranging and deep sensitivity analysis conducted.

The focus is on the direct beneficiaries within the primary research within this study. i.e.

- LiU 'active users' i.e. people living with long-term conditions for more than 12 months who are registered to use digital tools and contribute content to LiU and who use LiU more than twice per month; and,
- Family carers of people with long-term conditions, who may also have long-term conditions themselves.

Thus the SROI ratio calculated for LiU is reported as a SROI range rather than one single SROI figure.

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<sup>111</sup> BIAS, R. G. and MAYHEW, D. J., 2005. *Cost-justifying Usability: An Update for an Internet Age*. Burlington: Morgan Kaufman.

<sup>112</sup> See Appendix E for further evidence and discussion

There are also additional stakeholders who have been identified as material to the SROI based on the engagement process with LiU users and carers. Where possible, the data collected from services users can be used to infer an impact on these stakeholders. However, these stakeholders have not been directly engaged with during the evaluation due to the terms of reference set for the study, so only approximations have been used to calculate LiU's SROI. Such stakeholders are:

- Community-based organisations;
- Wide-spread local initiatives that are supported by LiU such as Get Active (personalised physical activity programmes for those with LTCs) and SmartCare (falls prevention); and,
- Care and NHS services.

### **Stakeholders not included in the SROI**

Equally, there are many stakeholders who are likely to experience a material impact as a result of LiU, but for whom there is no current evidence available in the cohort study. These are:

- a) Members of LiU, who sign up for and receive a monthly newsletter, the impact for whom is currently known nor recorded in such a way that can be included in a theory of change approach;
- b) Partners from a care and health sectors who have benefited via a corporate context; and,
- c) Local health and social care practitioners working within the local partnership structure for LiU, whose survey results are still in the collection phase, and so could not be included in the impact map.

The impact map, found in Appendix F, for LiU determines that at the current stage of development the range of returns to included stakeholders from the LiU investment is up to £2.80 returned for every £1 invested in LiU. The most likely return being positive i.e. more than £1.37 and up to £2.80 returned for every £1.00 invested. 'Chapter Five: SROI' and Appendix E give details about how this has been calculated.

## 7.7 Contributing to Scotland's health and care

Many of the conclusions point to Living it Up's blend of digital, interactive and community services meeting key drivers of health and care policy, especially in relation to policy governing quality and health inequalities in Scotland. These are now examined in brief.

### 7.7.1 Improving quality of health and care

The impacts arising from Living it Up support the six dimensions of quality asserted within two key Scottish policy papers ('Improving the Health & Wellbeing of People with Long-term Conditions in Scotland: A National Action Plan'<sup>113</sup>; and, 'The Healthcare Quality Strategy for NHSScotland - May 2010'<sup>114</sup>).

Adapted to reflect LiU's active user findings, the contribution made by Living it Up to the six dimensions of quality and long-term conditions held within both policy papers are:

- A. LiU is *Patient centred*: providing care and health lifestyles in a context that patients seek when diagnosed symptoms of their LTCs change. Being responsive to individual patient preferences, LiU's mix of online, national and community services value patient care and health decisions;
- B. LiU is *Safe*: helping active users to avoid harm from care and health that is intended to help them;
- C. LiU is *Effective*: providing individuals, active users, community and services with evidence-based scientific knowledge in a way that supports patients and/or carers to increase their expertise for self-care and self-management of long-term conditions. This in turn helps them to become 'expert patients';
- D. LiU is *Efficient*: helping to avoid waste by supporting health boards, community organisations, carers and councils to innovate and deliver service development in a person-centred way, that can result in self-reported levels of reduced use of care and health resources by active users;

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<sup>113</sup> THE SCOTTISH GOVERNMENT, 2009. *Improving Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan*. [online]. Edinburgh: The Scottish Government. Available from: [http://www.sehd.scot.nhs.uk/mels/CEL2009\\_23.pdf](http://www.sehd.scot.nhs.uk/mels/CEL2009_23.pdf) [Accessed February 2016].

<sup>114</sup> THE SCOTTISH GOVERNMENT, 2010. *The Healthcare Quality Strategy for NHSScotland*. [online]. Edinburgh: The Scottish Government. Available from: [www.gov.scot/resource/doc/311667/0098354.pdf](http://www.gov.scot/resource/doc/311667/0098354.pdf) [Accessed March 2016].

- E. LiU is *Equitable*: providing health and care lifestyle (diet, exercise, social/community, interactive user sharing via Blogs, tools etc.) advice that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socioeconomic status; and,
- F. LiU is *Timely*: possessing the potential to support patients when long-term conditions change after diagnosis and/or when co-morbidities present at any time of the day or night when assurance and safe advice is needed.

Source: Adapted from the Institute of Medicine<sup>115</sup>

Moreover, LiU's interactive tools within its online service permits active users to:

- Link with other innovations in care and health mechanisms at community level;
- Support customers/patients to tell their care and health professionals about their experiences, how they want their care and health advice to be delivered to improve the outcomes that are important to them and reduce potential harm to them, especially if living in rural and island locations;
- Be engaged in shared decision-making about their health and care;
- Connect with core and specialised health and care services without causing unnecessary delays and/or distress because of remote locations of where they live or when LTCs symptoms worsen; and,
- Manage self-directed care support and personalised care plans more adeptly by inviting them to reflect on their current self-care and self-management practices and aligning their self-care and self-management even when co-morbidities present.

The points listed above reflect many of the indicators of success within The Healthcare Quality Strategy for NHS Scotland (May 2010).

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<sup>115</sup> THE SCOTTISH GOVERNMENT, 2010. *The Healthcare Quality Strategy for NHSScotland*. [online]. Edinburgh: The Scottish Government. Available from: [www.gov.scot/resource/doc/311667/0098354.pdf](http://www.gov.scot/resource/doc/311667/0098354.pdf) [Accessed March 2016].

### 7.7.2 Health inequalities

The evidence from this evaluation also supports the view that the LiU initiative does make a positive contribution to supporting the action points listed within the Equally Well Report (2009)<sup>116</sup> generated by the Scottish Government Ministerial Task Force. Specifically:

- Action from national and local government and from other agencies including the NHS, schools, employers and Third Sector<sup>117</sup>;
- Effort at a community, national and online level directed at “killer diseases” such as heart disease, mental health and the harm caused by long-term conditions<sup>118</sup>; and,
- Uses this cross-cutting action between differing parties to address Scotland’s accessibility health gap to benefit its citizens, communities and the country as a whole<sup>119</sup>.

### 7.7.3 Scotland’s e-health, telehealth and telecare strategies

Indicative findings within this evaluation suggest that LiU provides a digital approach to prevention, enablement and to supporting independence, wellbeing, self care and self management in those managing a long-term condition in Scotland<sup>120</sup>.

Embodying key planks of Scotland’s e-health strategy vision (2014-2017)<sup>121</sup>, findings also show that those with LTCs who actively use LiU can be better supported through greater use of LiU because:

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<sup>116</sup> THE SCOTTISH GOVERNMENT, 2008. *Equally well, report of the ministerial task force on health inequalities*. [online]. Edinburgh: The Scottish Government. Available from: <http://www.gov.scot/resource/doc/229649/0062206.pdf> [Accessed March 2016].

<sup>117</sup> THE SCOTTISH GOVERNMENT, 2008. *Equally well, report of the ministerial task force on health inequalities*. [online]. Edinburgh: The Scottish Government. Available from: <http://www.gov.scot/resource/doc/229649/0062206.pdf> [Accessed March 2016].

<sup>118</sup> THE SCOTTISH GOVERNMENT, 2008. *Equally well, report of the ministerial task force on health inequalities*. [online]. Edinburgh: The Scottish Government. Available from: <http://www.gov.scot/resource/doc/229649/0062206.pdf> [Accessed March 2016].

<sup>119</sup> THE SCOTTISH GOVERNMENT, 2008. *Equally well, report of the ministerial task force on health inequalities*. [online]. Edinburgh: The Scottish Government. Available from: <http://www.gov.scot/resource/doc/229649/0062206.pdf> [Accessed March 2016].

<sup>120</sup> THE SCOTTISH GOVERNMENT, 2012. *A National Telehealth and Telecare Delivery Plan for Scotland to 2015 Driving Improvement, Integration and Innovation*. [online]. Edinburgh: The Scottish Government. Available from: <http://www.gov.scot/Resource/0041/00411586.pdf> [Accessed April 2016].

<sup>121</sup> THE SCOTTISH GOVERNMENT, 2015. *Scotland’s e-health strategy 2014-2017*. [online]. Edinburgh: The Scottish Government. Available from <http://www.gov.scot/Resource/0047/00472754.pdf> [Accessed April 2016].

- LiU enables information sharing and communications that may facilitate increased access to health and social care<sup>122</sup> across urban, island and rural settings from the patient's home to the hospital;
- LiU provides easy to follow tips, self-care tools and intelligence to customers of health and care services in Scotland, complementing the work of health and social care professionals, assisting with the improvement of the safety and quality of care people with long-term conditions receive<sup>123</sup>;
- LiU supports people to manage their own health and wellbeing and live longer, healthier lives at home or in a community setting<sup>124</sup>, reducing reliance on care services; and,
- LiU contributes to a partnership between the Scottish Government, NHSScotland, the third and commercial sectors that enable Scotland to be a long term leader in digitally enabled preventative care<sup>125</sup>.

Indeed, findings in this study provide an insight into how patients want to access, use and, share information with their health and social care providers in new and innovative ways using tools like LiU.

Findings also indicate how alternative forms of access to care and health services can help patients and carers aged 50 and over to make informed decisions to manage their health and wellbeing whilst managing a long-term condition. The findings also show that whilst LiU is still at an early stage of development, the blend of community and digital services shows how NHS24 and partners have developed a tool that puts customers front and centre of development and delivery in Scotland.

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<sup>122</sup> THE SCOTTISH GOVERNMENT, 2015. *Scotland's e-health strategy 2014-2017*. [online]. Edinburgh: The Scottish Government. Available from <http://www.gov.scot/Resource/0047/00472754.pdf> [Accessed April 2016].

<sup>123</sup> THE SCOTTISH GOVERNMENT, 2015. *Scotland's e-health strategy 2014-2017*. [online]. Edinburgh: The Scottish Government. Available from <http://www.gov.scot/Resource/0047/00472754.pdf> [Accessed April 2016].

<sup>124</sup> THE SCOTTISH GOVERNMENT, 2015. *Scotland's e-health strategy 2014-2017*. [online]. Edinburgh: The Scottish Government. Available from <http://www.gov.scot/Resource/0047/00472754.pdf> [Accessed April 2016].

<sup>125</sup> THE SCOTTISH GOVERNMENT, 2015. *Scotland's e-health strategy 2014-2017*. [online]. Edinburgh: The Scottish Government. Available from <http://www.gov.scot/Resource/0047/00472754.pdf> [Accessed April 2016].

## 8.0 RECOMMENDATIONS

### Recommendations

The following recommendations are made for consideration:

1. Given that the evaluation findings within this study are indicative and largely, act as a baseline of understanding of LiU, we suggest that a further evaluation takes place. This should take place in two stages. The first stage we recommend is that the same group of active users from the intervention group in this study are invited to take part in a follow-up user study to assess the additional developments of LiU's service in May 2016 on behaviour change, impact and accessibility. This follow-up study will provide verification or triangulation data to refine some of the assumptions made in this study.

The second stage we recommend is to undertake a far larger cohort study across the full complement of LiU's partner base, taking into account the dynamic between its mix of online and community services, specifically GetActive and Smartcare with the online services. A larger cohort study should explore and understand the effect between the digital and community services for beneficiaries in cohorts of specific long-term conditions such as COPD and heart conditions across Scotland and investigate what these are within rural, island and urban settings across specific demographic and psychographic criteria. Equally, an evaluation of this kind could evaluate LiU's effects on local policy-making and/or service delivery and roll-out specific to ehealth, telecare and telehealth strategies.

2. Future interventions that LiU adopts and rolls-out could be selected following a detailed assessment of the target group with long-term conditions, carers who care for them and carers who may also have long-term conditions themselves. An assessment such as this might examine beliefs, barriers, opportunities and competing factors that disrupt caring routines and so on.
3. Focus on specific self-care and self-management behaviours that the LiU team wish to support, and develop tools and content based around these.
4. Reconsider how LiU's service is positioned with regard to carers and how they are incorporated into LiU's service. Possibly link with carer organisations more explicitly and position content, local community groups differently and more directly to clarify tools, advice, tips and information aimed at supporting them at differing caring

junctures (e.g. assessments of the person they care for or by providing a 'typical week or day' tools).

5. Add very simple and 'fun' lifestyle tools to LiU like shopping lists and 'to do' lists for home modification after falling. Typical 'day in the life of' information when living with a specific long-term condition is cited as one of the key tools that is needed when a person is first diagnosed with a long-term condition or when symptoms worsen or change over time.
6. Findings suggest that LiU supports those with long-term conditions and/or carers to manage better at time of change or when co-morbidities may present. Developing additional content and tools around these times of worry and concern for active users could be very beneficial.
7. Develop an information flyer and provide brief seminars and training to frontline care and health staff about the benefits of steering those that they help and support to use LiU on an active basis to derive greater user numbers and further impact.
8. Ensure that accessibility and usability is at the heart of future developments on the LiU website. Carry out further usability testing involving those with long-term conditions, those with varying digital skill levels, disabled people as well as others who are part of the target group for the site.
9. Develop simpler ways for active users to contribute to the future developments of LiU and to share content online and within their communities. Users are likely to have tips and ideas for achieving self-care and self-management goals. Complement this by carrying out traditional search engine optimisation to tackle the modest growth rate of visitor numbers to LiU.
10. Undertake further, targeted social media campaigns to increase membership numbers so as more members become active users.
11. Adopt and integrate new interactive tools that are evidenced to improve well-being online into LiU's service, sign-posting the tips and advice that are intended to improve well-being in active users more clearly. For example, a Swedish study entitled *Physical exercise and internet-based cognitive-behavioural therapy (ICBT) in the treatment of depression: randomised controlled trial (2015) reported in the British Journal of Psychiatry (2015)*<sup>126</sup> that patients in the ICBT group reported the largest

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<sup>126</sup> HALLGREN, M., et al., 2015. Physical exercise and internet-based cognitive-behavioural therapy in the treatment of depression: randomised controlled trial. *The British Journal of Psychiatry*, 207(3), pp. 227-234.

*improvements in depressive symptoms compared with medical Treatment as Usual (TAU) by primary healthcare services<sup>127</sup>.*

12. Carefully select language used within LiU to reflect motivational interviewing and behavioural change grammatical structures which can prove helpful when challenging unhelpful beliefs. e.g. information on Living it Up could prompt goal setting wherever possible.
13. Encourage the members of LiU to become active users by marketing information to them directly and incentivising them to become more regular users in appropriate ways.
14. Forge a network of referral links for LiU within primary and secondary care within NHSScotland as well as the care sector by embarking on a targeted engagement programme to drive referral numbers via engagement within the public sector 'family'. This could use motivational interviewing training or 'managing patient expectations and/or managing challenging patient training' as an incentive for learning more about the benefits of LiU.
15. Re-structure LiU upon a clear theory of change that can assist both LTCs and well-being/physical health elements of LiU's services. Specifically, this might encourage greater levels of behaviour change and impact derived from active users. It could also provide a specific framework for generating web content on which future evaluations could be conducted.
16. Future consideration should also be given to developing an objective community adviser and site-survey to track the profile and usage of browsers, to include occasional users as well as delivering greater detail about the 1,000s of active users that benefit from LiU. This could enable greater web-analytic analysis to track who is using the site, when and why as well as to inform LiU's future service development.
17. Explore how LiU could provide an efficient and tangible way to help others linked within NHSScotland to meet preventative care obligations.

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<sup>127</sup> HALLGREN, M., et al., 2015. Physical exercise and internet-based cognitive-behavioural therapy in the treatment of depression: randomised controlled trial. *The British Journal of Psychiatry*, 207(3), pp. 227-234.

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# Appendix A - Glossary, Definitions and Report Overview

## Assets

Assets are the skills, talents and capacity that individuals, associations and organisations can share to improve the life of a community. An assets approach focuses on the strengths rather than the weaknesses (or deficiencies) found in groups or communities.

## Communities

For the purposes of this report, communities are defined as social or family groups linked by networks, peers, geographical location or another common factors and shared objectives.

## Determinants of health

The wide range of personal, social, economic and environmental factors which determine the health status of people or communities. These include health behaviours and lifestyles, income, education, employment, working conditions, access to health services, housing and living conditions and the wider general material and social environment.

## Health inequalities

The gap or gradient in health, usually measured by mortality and morbidity, between population groups identified by social characteristics, including different social classes, ethnic groups, wealth and income groups, genders, educational groups, housing and geographical areas.

## Interventions

Clearly circumscribed actions made by an organisation or individual that help promote or maintain a healthy lifestyle, including looking after a long-term condition and/or caring duties.

## Population

The aggregate of individuals defined by membership of a social, geographic, political or economic unit (for example, members of a state, a region, a city or a cultural group).

## Programmes

Multi-agency, multi-packages and/or a series of related policies, services and interventions or other actions focused on broad strategic issues. They can involve a suite

of activities that may be topic, setting or population based – and may involve changes to organisational infrastructures.

### Promoting and supporting behaviour change

A number of terms are used to describe attempts to promote or support behaviour change and sometimes these are used interchangeably. They include: initiative, scheme, action, activity, campaign, policy, strategy, procedure, programme, intervention and project.

### Resilience

The ability to withstand or even respond positively to stressors, crises or difficulties.

### Self-care

The actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital.

### Self-efficacy

Self-efficacy is a person's estimate or personal judgment of his or her own ability to succeed in reaching a specific goal.

### Self-management

Self management refers to the strategies used by people with long-term health conditions to deal with their symptoms, treatment, and the physical and/or social consequences of their illness.

### Social capital

Social capital is commonly defined as those features of a society, such as networks, social trust and cohesion, that facilitate cooperation among people for mutual benefit.

### Transition points

Points of change during a lifetime or the life course (for a definition of life course, see above). Examples include: leaving school, entering or leaving a significant relationship, starting work, becoming a parent or retiring from work.

## Definitions used

The study team at Impact Generation used the following definitions to guide the evaluation:

### 1. Behaviour change:

“The measurement of behaviour/s needs in the research design needs to hone beliefs (both positive and limiting), capacities, motivations, other’s attitudes (partners, friends, society’s, health and care professionals’) perceived benefits, competitive factors (access, etc.), barriers and other conditions that drive self-management behaviours”<sup>128</sup>.

### 2. Impact:

“Validated and observable social, cultural and economic patterns which limit - or enable - what individuals can do”<sup>129</sup>.

### 3. Access:

- “Quality of access, as measured by access to variety of choice, routes into accessing content; and,
- “The different types of activities undertaken using digital and online services”<sup>130</sup>.

### 4. Web Analytics Definitions:

According to the Web Analytics Association, there are three main types of Web analytics metrics: counts, ratios, and KPIs<sup>131</sup>:

- *Counts* are the most basic unit of measure; a single number, not a ratio. Often a whole number (Visits = 12,398), but not necessarily;
- *Ratios* are typically, a count divided by a count, although a ratio can use either a count or a ratio in the numerator or denominator. Usually, it is not a whole number. Because

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<sup>128</sup> NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE), 2007. *Guidance 6: Behaviour change: the principles for effective interventions*. London: NICE.

<sup>129</sup> NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE), 2007. *Guidelines [PH6]: Behaviour change: general approaches*. London: NICE.

<sup>130</sup> HELSPER, E., 2008. Digital inclusion: an analysis of social disadvantage and the information society. *Department for Communities and Local Government*, London, UK.

<sup>131</sup> BURBY, J., BROWN, A. and WAA STANDARDS COMMITTEE, 2007. *Web Analytics Definitions*. [online]. Washington, DC: Web Analytics Association. Available from: [http://www.digitalanalyticsassociation.org/Files/PDF\\_standards/WebAnalyticsDefinitionsVol1.pdf](http://www.digitalanalyticsassociation.org/Files/PDF_standards/WebAnalyticsDefinitionsVol1.pdf) [Accessed March 2016].

it's a ratio, "per" is typically in the name, such as "Page Views per Visit." A ratio's definition defines the ratio itself, as well as any underlying metrics<sup>132</sup>; and,

- *KPIs* (Key Performance Indicator) can be either a count or a ratio, it is frequently a ratio. While basic counts and ratios can be used by all Website types, a KPI is infused with business strategy – hence the term, "Key" – and therefore the set of appropriate KPIs typically differs between site and process types<sup>133</sup>.

A fourth type of definition included in web analytics is for terms that describe concepts or attachments made by users and visitors to online services. These are known as dimensions.

For the purposes of Living it Up, these are the concepts or dimensions of lifestyle, quality, health inequality and preventative health routines (such as self-care and self-management)<sup>134</sup>. A dimension is defined by the Web Analytics Association as:

- *Dimension* - A general source of data that can be used to define various types of segments or counts and represents a fundamental dimension of user/visitor behaviour or site dynamics<sup>135</sup>.

Moreover, the evaluation study was to produce a digital analytics statement (with regard to the LiU website) that describes: 'how evidence-based analytics improves health and well-being' based upon the findings. This statement is provided in 'Chapter 7: Conclusion' section of this report.

## **5. Return on Investment.**

The most appropriate mechanism chosen to assess LiU's ROI was Social Return on Investment:

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<sup>132</sup> BURBY, J., BROWN, A. and WAA STANDARDS COMMITTEE, 2007. *Web Analytics Definitions*. [online]. Washington, DC: Web Analytics Association. Available from: [http://www.digitalanalyticsassociation.org/Files/PDF\\_standards/WebAnalyticsDefinitionsVol1.pdf](http://www.digitalanalyticsassociation.org/Files/PDF_standards/WebAnalyticsDefinitionsVol1.pdf) [Accessed March 2016].

<sup>133</sup> BURBY, J., BROWN, A. and WAA STANDARDS COMMITTEE, 2007. *Web Analytics Definitions*. [online]. Washington, DC: Web Analytics Association. Available from: [http://www.digitalanalyticsassociation.org/Files/PDF\\_standards/WebAnalyticsDefinitionsVol1.pdf](http://www.digitalanalyticsassociation.org/Files/PDF_standards/WebAnalyticsDefinitionsVol1.pdf) [Accessed March 2016].

<sup>134</sup> BURBY, J., BROWN, A. and WAA STANDARDS COMMITTEE, 2007. *Web Analytics Definitions*. [online]. Washington, DC: Web Analytics Association. Available from: [http://www.digitalanalyticsassociation.org/Files/PDF\\_standards/WebAnalyticsDefinitionsVol1.pdf](http://www.digitalanalyticsassociation.org/Files/PDF_standards/WebAnalyticsDefinitionsVol1.pdf) [Accessed March 2016].

<sup>135</sup> BURBY, J., BROWN, A. and WAA STANDARDS COMMITTEE, 2007. *Web Analytics Definitions*. [online]. Washington, DC: Web Analytics Association. Available from: [http://www.digitalanalyticsassociation.org/Files/PDF\\_standards/WebAnalyticsDefinitionsVol1.pdf](http://www.digitalanalyticsassociation.org/Files/PDF_standards/WebAnalyticsDefinitionsVol1.pdf) [Accessed March 2016].

“SROI measures change in ways that are relevant to the people or organisations that experience or contribute to it. It tells the story of how change is being created by measuring social, environmental and economic outcomes and uses monetary values to represent them. This enables a ratio of benefits to costs to be calculated<sup>136</sup>.”

## **6. Long-term conditions.**

According to the Scottish Government, long term conditions are health conditions that last a year or longer, impact on a person’s life, and may require ongoing care and support<sup>137</sup>. The definition does not relate to any one condition, care-group or age category.

## **7. Prevalence of long-term conditions in Scotland.**

Around two million people, 40 per cent of the Scottish population, have at least one long term condition, and one in four adults over 16 report some form of long term illness, health problem or disability<sup>138</sup>. Long term conditions become more prevalent with age. According to Audit Scotland, the number of people aged 75 and over will rise by 60 per cent between 2004 and 2031. By the age of 65, nearly two-thirds of people will have developed a long term condition<sup>139</sup>.

Older people are also more likely to have more than one long term condition: 27 per cent of people aged 75-84 have two or more<sup>140</sup>. There is a predicted rise of 38 per cent in the number of people who will be over 85 in the population by 2016 and a 144 per cent rise in the over 85’s by 2031<sup>141</sup>.

The human costs and the economic burden for health and social care are profound. 60 per cent of all deaths are attributable to long term conditions and they account for 80 per cent of all GP consultations<sup>142</sup>.

## **9. Defining a carer.**

<sup>136</sup> NICHOLLS, J. et al., 2012. *A guide to Social Return on Investment*. Glasgow: The SROI Network.

<sup>137</sup> THE SCOTTISH GOVERNMENT, 2015. Long Term Conditions. [online]. Edinburgh: The Scottish Government. Available from: <http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions> [Accessed February 2016].

<sup>138</sup> AUDIT SCOTLAND, 2007. *Managing long-term conditions*. [online]. Edinburgh: Audit Scotland. Available from: [http://www.audit-scotland.gov.uk/docs/health/2007/nr\\_070816\\_managing\\_long\\_term.pdf](http://www.audit-scotland.gov.uk/docs/health/2007/nr_070816_managing_long_term.pdf) [Accessed February 2016].

<sup>139</sup> THE SCOTTISH GOVERNMENT, 2015. Long Term Conditions. [online]. Edinburgh: The Scottish Government. Available from: <http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions> [Accessed February 2016].

<sup>140</sup> AUDIT SCOTLAND, 2007. *Managing long-term conditions*. [online]. Edinburgh: Audit Scotland. Available from: [http://www.audit-scotland.gov.uk/docs/health/2007/nr\\_070816\\_managing\\_long\\_term.pdf](http://www.audit-scotland.gov.uk/docs/health/2007/nr_070816_managing_long_term.pdf) [Accessed February 2016].

<sup>141</sup> AUDIT SCOTLAND, 2007. *Managing long-term conditions*. [online]. Edinburgh: Audit Scotland. Available from: [http://www.audit-scotland.gov.uk/docs/health/2007/nr\\_070816\\_managing\\_long\\_term.pdf](http://www.audit-scotland.gov.uk/docs/health/2007/nr_070816_managing_long_term.pdf) [Accessed February 2016].

<sup>142</sup> EQUAL PARTNERS IN CARE (EPiC), 2013. *Core principles for working with carers and young carers*. [online]. Edinburgh and Dundee: NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC). Available from: <http://www.knowledge.scot.nhs.uk/media/6525401/core%20principles.pdf> [Accessed February 2016]

A carer is someone who provides unpaid support to a family member or friend<sup>143</sup>. They may care for an older person, someone who is disabled, has a long-term illness, mental health problems or is affected by alcohol or drug misuse<sup>144</sup>. Carers can be any age, from children to older people, and from every community and culture. Some carers may be disabled or have care needs themselves. They may be parents, spouses, grandparents, daughters, brothers, same sex partners, friends or neighbours<sup>145</sup>.

## Policy Context

### **Policy regarding holistic services tackling long-term chronic conditions**

The approach taken to design Living it Up is supported and embedded into key planks of health and care policy. Including:

1. The Healthcare Quality Strategy for NHSScotland (2010);
2. Improving Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan, The Scottish Government (2009);
3. Equally well, report of the ministerial task force on health inequalities. The Scottish Government (2008);
4. Scotland's e-health strategy 2014-2017;
5. A National Telehealth and Telecare Delivery Plan for Scotland to 2015 Driving Improvement, Integration and Innovation;
6. The Health Innovation Partnership (Medical Technologies) Scottish Government (2012): "Health and Wealth in Scotland: a Statement of Intent for Innovation in Health"; and,
7. The Digital Health and Care Innovation Partnership.

The British Medical Association (BMA) is championing a more holistic point of view for caring for long-term conditions via behaviour change. In its 'Position Statement: Behaviour change, public health and the role of the state (December 2012)' the BMA states:

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<sup>143</sup> EQUAL PARTNERS IN CARE (EPiC), 2013. *Core principles for working with carers and young carers*. [online]. Edinburgh and Dundee: NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC). Available from: <http://www.knowledge.scot.nhs.uk/media/6525401/core%20principles.pdf> [Accessed February 2016]

<sup>144</sup> EQUAL PARTNERS IN CARE (EPiC), 2013. *Core principles for working with carers and young carers*. [online]. Edinburgh and Dundee: NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC). Available from: <http://www.knowledge.scot.nhs.uk/media/6525401/core%20principles.pdf> [Accessed February 2016]

<sup>145</sup> EQUAL PARTNERS IN CARE (EPiC), 2013. *Core principles for working with carers and young carers*. [online]. Edinburgh and Dundee: NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC). Available from: <http://www.knowledge.scot.nhs.uk/media/6525401/core%20principles.pdf> [Accessed February 2016]

“Lifestyle-related disease represents the most pressing public health threat of modern times and these diseases have a strong social gradient, disproportionately harming the most disadvantaged. In the BMA’s view, tackling these problems by relying largely or exclusively on personal responsibility, ‘nudging’ individuals and corporate social responsibility is inadequate. It is also likely to entrench existing inequalities”<sup>146</sup>. Therefore, a more supportive environment for self care and self management, linking into public services where and when appropriate would seem logical and potentially effective. LiU has progressed an on-line model to address this.

## Report structure

### Chapters and appendices

This report is divided into seven chapters and is supported by five Appendices.

#### *Report chapters*

There are seven report chapters. The seven chapters are listed below:

- Chapter 1: Evaluation method
- Chapter 2: Behaviour change findings
- Chapter 3: Impact findings and analysis
- Chapter 4: Accessibility findings and analysis
- Chapter 5: Social Return on Investment
- Chapter 6: Conclusions
- Chapter 7: Recommendations

The report is also supported by a glossary of terms situated at the front of this report.

#### *Appendices*

There are six appendices labelled A, B, C, D, E and F. These are listed next:

- Appendix A: Glossary
- Appendix B: Secondary desk report
- Appendix C: Deliberative event report
- Appendix D: Statistical analysis graphs, figures and list
- Appendix E: Data analysis tables and graphs used to determine accessibility

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<sup>146</sup> BRITISH MEDICAL ASSOCIATION (BMA), 2012. *Behaviour change, public health and the role of the state - BMA Position Statement*. London BMA.

- Appendix F: Impact Map used to determine a social return on investment value for living it Up

### **Report chapters in more detail**

*Chapter one* details the research design and method of each type of evaluation within this report.

*Chapter two* describes the extent of behaviour change detected amongst the study participants given the evaluation findings.

*Chapter three* determines the level of impact or difference that LiU has made to those with long-term conditions and/or carers when using a theory of change analysis.

*Chapter four* assesses Living it Up's accessibility in light of WC3 industry standards.

*Chapter five* details the thinking and approach used to calculate a Social Return on Investment (SROI) figure that can be attributed to LiU and ascribes a SROI value range.

*Chapter six* describes general conclusions that can be drawn from the findings and analysis and looks at specific conclusions against behaviour change, impact, accessibility and SROI.

*Chapter seven* makes key recommendations for Living It Up's future development and future monitoring and evaluation.

### **Appendices in more detail**

The six Appendices note:

Appendix A: Glossary

Appendix B: Secondary desk report.

Appendix C: Deliberative event report.

Appendix D: lists the full statistical tables and graphs analysed from the primary research.

Appendix E: outlines the statistical graphs and data analysis tables that have been used to determine accessibility for 'Living it Up'.

Appendix F: details the impact map that has been used to calculate the SROI for 'Living it Up'.