

PERSONALISING REALISTIC MEDICINE

Chief Medical Officer's Annual Report 2017-2018



'Variability is the law of life, and as no two faces are the same, so no two bodies are alike, and no two individuals react alike and behave alike under the abnormal conditions which we know as disease.'

William Osler (1849-1919)

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INTRODUCTION FROM THE CHIEF MEDICAL OFFICER

INTRODUCTION



Three years ago, when I framed my first Annual Report around six questions and called it *Realistic Medicine*, I asked you whether we could achieve a new paradigm of care for the people in Scotland. My vision reflected what was emerging from my conversations across the country about how people wanted to provide and receive care.

It was evident back then that the desire to provide a more personalised approach to care was dominating these conversations. Over the last 3 years, enthusiasm around the personalised approach has continued to build and it is now clear to me that it has become the central theme in people's minds when they think about delivering Realistic Medicine. I hear this when I speak to professionals and to patients, I recognise this when I observe the changes that people have made to their clinical practice and I see this when I review the findings of our Realistic Medicine Survey and the recommendations of our Citizens' Jury.

So, in acknowledgement of its importance, I am keen to explore 'Building a Personalised Approach to Care'. How do we personalise Realistic Medicine for our patients and for our staff? How do we overcome the challenges in our system to deliver this care? How do the other domains of Realistic Medicine contribute to us achieving our aim?

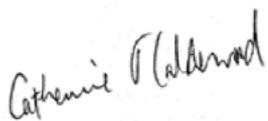
I am aware that, for many, my Annual Report is the most prominent example of our work to deliver the vision of Realistic Medicine. However, our work programme does not end when the reports are published. Much has been achieved in creating the conditions that enable Realistic Medicine to flourish and, over the last 12 months, there have been some exciting developments that are critical to this.

- We have funded 20 **Realistic Medicine Clinical Lead** posts across NHS Scotland to champion Realistic Medicine in local health and social care systems. In addition, 8 Realistic Medicine Finance Leads have been appointed across the country to encourage closer links between clinical and finance colleagues and to promote a culture of stewardship and value based healthcare.
- In August 2018, we launched the **Value Based Healthcare Improvement Project Fund**, inviting bids from NHS Boards for local projects that will achieve value based healthcare. 50 applications were received and 11 projects were successful in securing funding for 2 years. If these projects evaluate well, there is a commitment from Medical Directors to continue to support roll-out once central funding comes to an end.
- In September 2018, we launched the **Scottish Atlas of Healthcare Variation**, in collaboration with Information Services Division (ISD) Scotland. To date, eighteen maps have been published within the Atlas. The Atlas work is discussed in more detail later in the report (see page 31/32).
- In October 2018, we explored the attitudes of health and social care professionals by conducting a **Realistic Medicine Survey**. In total, 2,464 responses were received. The survey has provided us with valuable insight into the barriers to practising Realistic Medicine as well as what our future priorities should be in order to achieve the 2025 vision. A summary of the survey results are presented in Appendix 1 (page 43/44).
- In October 2018, we held our annual **Realistic Medicine Conference** in Dunblane. The theme of the conference was 'Valuing People' and over 300 people attended. Keynote speakers included Dr Al Mulley, a world renowned expert on personalised care and shared decision-making, and Professor Richard Lehman, a weekly columnist in the British Medical Journal and Chair of the Preventing Overdiagnosis through the Shared Understanding of Medicine (POSSUM) group. Those who attended also had the opportunity to get involved in workshops on practising shared decision-making, Schwartz Rounds and the Scottish Atlas of Healthcare Variation. The feedback received was overwhelmingly positive.

- In October and November 2018, we held Scotland's first ever **Citizens' Jury** on a health topic. Over 3 weekends, the Jury considered the question '*what should shared decision-making look like and what needs to be done for this to happen?*'. The Jury made 13 recommendations for consideration by the Scottish Government and presented them to the Chief Medical Officer on 6th February 2019. The Jury process and recommendations are discussed in more detail later in the report (see page 15/16).
- In December 2018, we launched a **Realistic Medicine Website**. It contains a range of information and resources to support professionals to practise Realistic Medicine and it can be accessed here: <https://www.realisticmedicine.scot/>. The site also provides details about the Realistic Medicine Leads for each area, inspiring examples of good practice, resources to support practice of Realistic Medicine, and a news feed with the latest updates from the Realistic Medicine team.

I could not do any of this on my own and I am grateful for the support of my Realistic Medicine team, who are deeply committed and work incredibly hard to ensure that these elements come together successfully.

But, whilst they create the conditions for Realistic Medicine to develop and grow, it is you, all around the country, who are making it come alive. Once again, I thank you for your continued support and congratulate you on your considerable achievements, many of which can be found within the rest of this report. You are the people who are delivering this vision. It is because of you that I am committed to *Personalising Realistic Medicine*.



Dr Catherine Calderwood MA Cantab FRCOG FRCP Edin
Chief Medical Officer for Scotland

CHAPTER 1

PERSONALISING REALISTIC MEDICINE FOR OUR PATIENTS

In my third annual report, *Practising Realistic Medicine*, I stated that *'building a more personalised approach to care is perhaps the most important aim of Realistic Medicine and perhaps one of our greatest challenges'*.¹ Just six months later, the findings from the Realistic Medicine survey confirmed that you agree: 37% of those who responded, by far the largest percentage, ranked this principle as their top priority for Realistic Medicine. But what does a personalised approach to care really look like and what can we do to deliver it?

WHAT IS A PERSONALISED APPROACH TO CARE?

The idea of understanding people in order to be able to care for them is not new. Over 2000 years ago, Hippocrates observed that:

'it is more important to know what sort of person has a disease than to know what sort of disease a person has'.

At times, though, it can feel like healthcare is heading in the opposite direction, its roots growing away from the patient. There is often a disconnect between what patients want and need and what health professionals **believe** patients want and need. We must stop this from happening.

Victor Montori is Professor of Medicine at Mayo Clinic in the United States and Chair of the Board of The Patient Revolution, an organisation advocating for better patient-centred care. Victor is vocal about his fears:

'as we professionalise and industrialise the management of healthcare, the patient becomes a blur, an entity that is almost mythological, a number, a statistic, some object that we put through a conveyer belt, something that we move from point A to point B and manage'.

This is a sobering assessment but one which has resonance with Dr Al Mulley's warning in *Realising Realistic Medicine* to avoid reductionist approaches to care.² It is a message that all health services, including our own, must heed. This is not the care that we would want for ourselves or our families. It should not be the care we provide.

As Victor explains, with a growing number of people now living with multiple, complex and frequently fluctuating health conditions, the need for a personalised approach is greater than ever:

'Personalised care is particularly important for people living with chronic conditions that we cannot fix. If the healthcare system can meet their needs, it can almost certainly meet the more straightforward needs of people with single complaints that are self-limiting or easily fixable. But patients with chronic conditions keep coming back. They need to come back. They need our partnership and support. But, more importantly, they need their care to be aligned with the other things that are going on in their lives. Without a deeper understanding of their lives, there is limited hope for us to be effective in helping them. We must not only address their symptoms but also support their goals, their ability to adapt to their condition and their ability to self-manage, so that they are less dependent on us as health professionals when living their lives and pursuing their hopes and dreams. In this regard, personalised care is not just a "nice to have" but a "must have".'

To deliver a more personalised approach for our patients, Victor champions a vision of 'careful and kind care'. Careful care is founded on principles of quality, safety and best available evidence but, more importantly, considers a person's biology (their disease and comorbidities) in the context of their biography (their life situation and priorities). Kind care is respectful of a person's most precious resources – their time, energy and attention – and tries to minimise the impact of healthcare upon these.³

I am fully aware that many of us practise healthcare in this way. However, in a complex and pressurised healthcare system, we must do more to 'live' the core principles of 'careful and kind care' and learn from new examples of good practice.

WHAT CAN WE DO TO DELIVER CAREFUL CARE?

In my previous Annual Reports, I have spoken of the need to involve people actively in decisions about their care.^{1,2,4} We must make a more concerted effort to identify what matters most to them.

'We need to notice and understand the person and, by focussing on learning something new, we can clarify either the content of the healthcare problem or the context in which it is playing out'.

Victor Montori

Many clinical teams have now adopted a version of a 'what matters to you' conversation into their practice and, in doing so, have been able to personalise the treatment and care they provide. Adopting this approach often results in a psychological shift in culture where finding out 'what matters to you' simply becomes the way things are done. Box 1 shares a powerful testimony.

Box 1 - What Matters To You

Jennifer Rodgers is Chief Nurse for Paediatric and Neonatal Services across NHS Greater Glasgow and Clyde

On hearing about flipping the question 'what's the matter with you?' to 'what matters to you?', I immediately returned to my ward with an idea to ask all the children to draw posters about what mattered to them. The posters would be placed above their beds or on their doors. Very quickly, I realised we made assumptions about what mattered to children. Often what they said surprised me: 'that I get the right medicines'; 'that I get a good night's sleep'; 'that I am safe'; 'talk to me, not just my mum and dad'; 'doctors see me, not my illness'; 'doctors keeping their promises'. I then used quality improvement methodology to ensure we built a reliable process for collecting data on process and outcome measures.

Stories began to emerge. For example, Kendra was admitted to the children's hospital with her dad. Together, they completed their poster but a short time later he was rushed to an adult hospital leaving Kendra on the ward without her main carer. Kendra had autism and had her own unique way of communicating. The poster enabled hospital staff to understand and care for Kendra. They knew she may try to 'make a run for it', and that she didn't like getting her medicines. Kendra's way of saying hello was touching or even pulling peoples' hair. If the staff had not known this, they may have interpreted this as aggressive behaviour and managed the situation very differently.

Over the past 7 years, I have been spreading the use of 'what matters to you' posters to paediatric departments across Scotland and also collaborating with colleagues in adult services. In 2016, we had our first 'What Matters to You' day. A year later, more than thirty countries took part.

Asking what matters doesn't just help us get to know people better. It gives families and staff permission to say things which otherwise would go unsaid. When my dad was in his final weeks, he was admitted to a Glasgow hospital. I sat with him to complete his 'What Matters To Me' poster. In that moment, he told me that I mattered to him and that he was proud. Without the prompt of the 'what matters' conversation that would have remained unsaid.

Health and social care teams are also capturing the essence of 'what matters to you' in other ways. In *Practising Realistic Medicine*, I discussed the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT), a process that creates personalised recommendations for a person's clinical care in a future emergency where they are unable to make or express choices.¹

**'Thanks for taking the time to sit down and actually listen to what I have to say'.
PACT patient**

An innovative approach to care planning introduced by the Patient Experience and Anticipatory Care Plan Team (PACT) in NHS Lothian builds on this further. Here, clinicians working at the hospital front door recognised that there was a small group of patients who frequently presented to hospital in acute crisis. PACT uses an algorithm to identify Emergency Department (ED) frequent attenders and other patients at very high risk of hospital admission. Each patient is allocated to the most appropriate PACT key worker, who is an experienced ED charge nurse or consultant or, where relevant, an addictions or psychiatric nurse or consultant. When the patient presents to hospital, the key worker takes this opportunity to empathise and engage fully and to motivate behaviour change. The PACT key worker and the patient work together, usually collaborating with others including relatives, carers, the patient's GP and wider hospital team to develop an Anticipatory Care Plan (ACP), which is uploaded onto the patient's hospital record. The ACP then guides staff managing future presentations to the ED. A secure electronic copy of the ACP is shared with the patient's GP in a format compatible with the Key Information Summary, enabling access by out-of-hours GP services and the Scottish Ambulance Service. A copy of the plan is also shared with the patient and anyone else that the patient wishes. To date, PACT has completed over 1,000 patient-centred care plans, and feedback from patients, relatives and staff has been overwhelmingly positive.

In 2018, mental health services in Scotland developed Transition Care Plans (TCPs) to empower young people to play an active role in their transition from Child and Adolescent to Adult services. The TCP gives young people the opportunity to express their needs, wants, preferences and concerns ahead of the move so that the transition can be attuned as closely as possible to what is important to them.

A multidisciplinary approach to delivering personalised care can be very effective. The Silver City project in Aberdeen City Health and Social Care Partnership uses a community multidisciplinary team (MDT) model to build resilience for people living with frailty. The MDT includes a GP, Community Geriatrician, Care Manager, Allied Health Professionals, District Nurses, a Community Geriatric Nurse, Practice Pharmacist, Community Link Practitioner and third sector representatives. They meet regularly in participating GP surgeries.



For each patient, the team tries to establish the person's life goals and tailor their interventions to achieve them. The collaboration between GP and Geriatrician enables expertise to be shared on the patient's illness and their life situation and priorities, 'the biology and biography' highlighted by Victor Montori. The MDT also identifies opportunities to improve wellbeing (including polypharmacy reviews and signposting to activities) and shares their suggestions with the patient. Although every meeting has these features in common, the MDT approach at each GP surgery is different, drawing on local assets and reflecting community and individual need. The project has been well received by patients and staff. For many people, their pattern of interaction with primary care services has been converted from reactive and disordered to planned and proactive. Crucially, the focus of their care is now on achieving what matters most to them.

**'The effort that you put in to being present and curious is rewarded by the knowledge that this particular person got a little bit better, a little bit of "health", from meeting with you'.
Victor Montori**

WHAT CAN WE DO TO DELIVER KIND CARE?

To rise to Victor's challenge to deliver kind care, we need to think creatively. How can we minimise the impact of our care on a person's time, energy and attention? How can we design our services and adapt our practices to engage patients in their care? How do we involve people without overwhelming them?

We must be sure that we are delivering the right care to the right people at the right time in the right place. Put simply, we must deliver better value care. A good example of this is the Distress Brief Intervention (DBI) Programme. In 4 pilot areas in Scotland, people in distress are being offered alternative person-centred support by front-line emergency services (Emergency Departments, Police Scotland, Scottish Ambulance Service and Primary Care). DBI is a two level approach to de-medicalise distress and care for people as citizens rather than as patients.



In DBI level 1, trained front-line staff provide a compassionate response and, if further emergency support is not required, offer referral to DBI Level 2 distress workers. DBI level 2 is provided by commissioned and trained third sector staff at a place and time to suit the person. DBI staff guarantee contact within 24 hours of referral and provide supportive listening, compassionate community-based problem solving, signposting, and wellness and distress management planning for up to 14 days. Early observations show very positive experiences and outcomes for both the person in distress and front-line services. A formal evaluation will be completed by the University of Stirling by 2021 as an action of the *Mental Health Strategy 2017-2027*.⁵

Guided by similar principles, maternity and neonatal services continue to evolve to support parents to be the primary carers for their baby at this early but critical stage of life. In 2017, Scottish Government published *The Best Start: A Five-Year Forward Plan for Maternity and Neonatal Care in Scotland*.⁶

Two recommendations focus specifically on building a personalised approach to care:

- Maternity and Neonatal Care should be co-designed with women and families from the outset, with information and evidence provided to allow her to make informed decisions in partnership with her family, her midwife and the wider care team as required.
- Services will regard mother and baby as one entity and truly put the mother, baby and family at the centre of service planning and delivery.

One early success for Best Start has been the new transitional care service in NHS Forth Valley. Here, maternity and neonatal services collaborate to support parents and babies to stay together on the postnatal ward. This includes helping parents to learn key aspects of care, such as nasogastric feeding. The bed space and staffing within the ward has also been reconfigured to enable the transitional care service to flourish. The changes have been welcomed by families and have resulted in fewer admissions to the neonatal unit, reducing separation of mother and baby and maximising opportunities for attachment and bonding. The work was awarded the Best Poster Prize at the 2018 Realistic Medicine Conference.

'Very valuable (service) as it doesn't break the bond between the mother and baby. The most important thing is for a mother to be with her child'. Mother receiving Best Start transitional care



Technology-enabled care also offers new ways of engaging with people and opportunities for providing kind, minimally-disruptive care. Its value is highlighted in *Scotland's Digital Health and Care Strategy* published in 2018.⁷

Home and Mobile Health Monitoring (HMHM), sometimes referred to as 'telehealth', is the use of digital remote monitoring technology to enable people outside of hospital to receive, record and relay information about their health and wellbeing. HMHM is in use across Scotland with protocols developed for conditions relating to some of the country's top health priorities, such as mental health, hypertension, heart and respiratory disease and diabetes.

There is strong evidence to demonstrate that, due to HMHM, more people are now taking responsibility for and self-managing their health.⁸ Access to services has improved and face-to-face contacts have been optimised.

Technology can also be used for healthcare consultations. 'Attend Anywhere' provides a video clinic service that people can access using their own

Box 2 - NHS Near Me

Clare Morrison is Lead for NHS Near Me in NHS Highland

NHS Near Me is a new digital service providing outpatient appointments closer to home using video consulting. It was created in response to patient demand to reduce travel to appointments in Raigmore Hospital, Inverness. It uses the Attend Anywhere platform but the difference in NHS Highland is that a systematic quality improvement approach was taken to introduce it. This involved co-design with patients, clinicians and other NHS staff for six months before a process was agreed for scale-up. NHS Near Me scale up began in September 2018.



The service includes:

- Video calls requiring clinical support: 4 staffed NHS Near Me clinics in locations over two hours from Raigmore Hospital.
- Video calls from home: patient uses own device (e.g. smartphone) or, to ensure equitable access, one of 15 NHS Near Me rooms.

As of January 2019, 17 clinical departments are providing NHS Near Me consultations, with more about to start. Our Haematology department is now the number one provider of NHS Near Me/Attend Anywhere consultations by volume anywhere in Scotland, with several other Highland services in the top 20. In Caithness, we are already providing 8% of outpatient appointments by NHS Near Me. This means almost 80 patients a month are now avoiding travel to Inverness.

NHS Near Me enables us to provide appointments where patients want them, rather than expecting patients to fit their lives around the NHS. It reduces health inequalities related to access and limits the detrimental effects of having to travel for appointments - for frail patients and relatives, it is less exhausting; for others, less time needs to be taken off work or school.

'I wish this service had been in place when my husband was alive. We spent the last year of his life driving up and down to Raigmore for hospital appointments. Avoiding this would have given us much more quality time together before he died'.

Patient

'Having an appointment at home meant I didn't have to go outside in icy weather or get someone to watch my husband'.

Patient, carer for husband

web browser. Attend Anywhere has been established in 13 NHS Boards as well as in Health and Social Care Partnerships and third sector organisations across Scotland. Box 2 summarises its impact in one Scottish board.

There are other simple and effective ways in which we can help our patients. Each week, thousands of letters are sent about patients in Scotland but rarely are they shared with the person concerned. Excluding people from their letters, or indeed including them in letters that use technical or clinical language, feels at odds with the meaningful conversations we must have to facilitate shared decision-making. Two of our Realistic Medicine Leads have recently changed their practice and now write directly to their patients.

Dr Steinunn Boyce is a Realistic Medicine Clinical Lead in NHS Fife and a Consultant in Palliative Medicine. In her clinic, discussions about deteriorating health and prognosis are commonplace. She asks permission to write directly to patients, copying in their GP and other clinicians. To date, no-one has declined this offer. The

letters serve as a useful reminder of what has been discussed and agreed during the consultation. They also enable people to share this information with family, carers and friends.

**'Letters can empower the person and those close to them to play a more active role in future decisions about their care'.
Steinunn Boyce**

One letter resulted in a conversation with a patient who felt that her prognosis had been over-estimated. Another patient shared her letter with relatives abroad, improving the family's understanding of her illness. Importantly, this prompted her relatives to arrange an earlier visit home. No-one has expressed shock at writing to them about subjects such as prognosis, "do not attempt cardiopulmonary resuscitation", changing future care needs and the dying process. This is most likely because the content of the letter is a reflection of the honest and compassionate conversation already shared in person in the clinic. Box 3 showcases a selection of real extracts from Dr Boyce's letters.

Box 3 - Extracts from palliative care clinic letters written directly to patients

'You and your wife are coming to terms with the fact that there is no further treatment for your ... cancer. You understand that the cancer has got worse despite the chemotherapy and, given how unwell it made you, further treatment would probably do more harm than good.'

'Although you are keen to remain at home, you are also very mindful of the impact of this on your family. If things were to become difficult you would prefer an admission to the hospice either for symptom control or end of life care.'

'You admitted you are feeling quite angry about what is happening to you, but are not frightened about what is to come. [Your wife] was very keen to talk about how long you might have, and with your permission I explained that it was likely that time was measurable in months. You did not appear shocked by this. I explained that it is very difficult to predict but often the rate at which your condition is deteriorating, such as energy levels and ability to do normal activities, can indicate timeframes.'

Dr Ewan Bell is the Realistic Medicine Clinical Lead in NHS Dumfries and Galloway and a Consultant Biochemist. He now writes to his patients living with diabetes directly and shares his letters with their GP. Dr Bell's letters use non-technical language to set out the agreed treatment plans and remind his patients of how and when to attend their next appointment. His letters also explain how people can access their test results online. If appropriate, he provides them with a patient-initiated follow-up appointment rather than a routine booking. To assess the impact of his changes, Dr Bell surveyed his patients and their GPs. 38 patients and 33 GPs responded, a return rate of 45% and 65% respectively. Feedback was very positive. Both groups agreed that his letters have helped empower patients to manage their diabetes effectively. 90% of patients liked getting their letter directly, 80% felt more involved in decisions about their health and care, 70% felt it helped them understand their diabetes better and 60% of patients liked being in control of their next appointment. 80% of GPs liked the style and format of the letter and felt it was detailed enough to provide them with the up-to-date information they needed. The next step is to measure the impact of Dr Bell's approach on patient compliance to agreed treatment plans and the impact on clinic waiting lists.



The Academy of Medical Royal Colleges has now adopted the 'Please, write to me' ('letters to patients') initiative⁹ as part of its commitment to person-centred care and it is entirely consistent with the General Medical Council's *Good Medical Practice* which states:

'You must give patients the information they want or need to know in a way they can understand'.¹⁰

I am very supportive of this approach and would like to see it used more extensively across Scotland.

We must also build the same personalised approach in social care. The Three Conversations Model, currently being introduced by Edinburgh Health and Social Care Partnership and already established elsewhere in the UK, is one example of how this can be achieved. Here, care workers and social workers are trained to have a sequence of three conversations with people who need support. The overarching aim is to help people lead independent lives by identifying their goals, unlocking their own resources and connecting them to the assets of their community. Traditional support packages are offered only when other options have been exhausted. The stages are outlined below:

- Conversation 1: Listen and Connect [*initial contact to understand what really matters*] - what do you want to do and how can I connect you to resources and support that will help you to achieve this?
- Conversation 2: Work Intensively with People in Crisis [*when people are at risk*] - what needs to change urgently to make you safe and help you regain control of your life, and how can I help make that happen?
- Conversation 3: Build a Good Life [*when long-term support is needed*] - what does a good life look like, what resources and connections will enable you to live this life, and how do these need to be organised?

The principles of both careful and kind care are evident in this model. There is an emphasis on understanding what matters to the person and on decision-making in partnership. There is also a conscious move away from the more conventional 'sorting office' approach to social care, characterised by waiting lists, triage and lengthy, tick-box, form-led assessment, in favour of a more responsive and collaborative model. Approaches such as this will help us to deliver better value care to those choosing to live at home, or in a homely environment, and will enable staff across our integrated health and care system to provide Realistic Medicine.

CONCLUSION

This chapter opened with the question 'what does a personalised approach to care really look like?'. It concludes with two answers.

First, we must focus on the person and achieve a better understanding of their preferences and values. This does not mean that we always give people what they want because we know that there are times when it may not be appropriate or practical for us to do so. But we should always consider what matters to them and try to better understand how their disease and our treatment fits into the broader context of their lives.

Secondly, we must focus on the service we provide. Where is there too much medicine? Where are we creating unnecessary work for those receiving our care?

To practise Realistic Medicine, we need to consider both of these areas. We should take the time to talk to our patients about their lives and then use our experience and clinical judgement to deliver true evidence-based medicine in a personalised way.¹¹ This is an approach of which Hippocrates would approve.

CHAPTER 2

THE CHALLENGES OF PERSONALISING REALISTIC MEDICINE

For most health and social care professionals, the major barriers to delivering Realistic Medicine are not ideological. In fact, 95% of those who responded to our survey felt that the principles of Realistic Medicine fully or somewhat matched their own personal beliefs and values about how healthcare should be practised. The greater challenge is how to practise Realistic Medicine in our current healthcare landscape.

ENGAGING OUR PATIENTS

If we are to realise the vision that everyone will be practising Realistic Medicine by 2025, we need to engage more effectively with our patients. This means shifting the culture of communication away from the traditional paternalism of 'doctor knows best', and toward a collaborative partnership of shared decision-making between professional and patient. Professionals must endeavour to build trusting relationships and maintain a dialogue of openness and honesty. People must truly feel comfortable asking questions about their care and they must be reassured that their beliefs, choices and preferences will not diminish the quality of care that they receive. Similarly, professionals must feel able and willing to ask the right questions and give clear, honest and realistic answers.



Engaging the public is more complex. There are an array of different approaches and which works best depends partly on the nature of the conversation and the subject matter. For example, surveys work well with topics which people may already be quite knowledgeable about, or have had the opportunity to develop an opinion on, but do not work as well if people are less familiar with the topic. Another consideration is that there is rarely, if ever, a single public view on anything. In fact, taking this further, some have argued that 'the public' does not actually exist.¹² Real people have real lives, real stories, real problems and real priorities and, therefore, no person is a 'typical' member of the public. So, when engaging with the public, one tends to encounter a diversity of views, sometimes with only subtle yet important differences. Capturing such views can be more of an art than a science.

We must also remember that 'how' we engage constructs the public we engage with. If we engage with them as thoughtful and reflective citizens, we encounter a different public to the one we encounter through surveys or the media. This is the reason why deliberative methods of public engagement, such as Citizens' Juries, are increasingly being used to understand what citizens think about particular topics.¹³ This is why I considered it appropriate to use a Citizens' Jury to ask members of the public for their thoughts on shared decision-making. And so, last year, Scotland held its first ever Citizens' Jury on a health topic.¹⁴

The Jury has been a fascinating and most valuable exercise that has given us the opportunity to reflect on how we can get better at shared decision-making. Box 4 describes the process and the recommendations that the Jury has made. I am aware that some have expressed concerns around whether the public are willing to be engaged on Realistic Medicine and even whether the public can be 'realistic'. I do not believe that either concern is founded and this process has provided further evidence that, when provided with the information they need, the public can make practical and very sensible recommendations about how to provide better value care. Having sent 3000 letters of invitation, 269 applications were received, an overwhelming response rate for this process. All Jury members attended all three sessions (all on different Saturdays throughout October and November 2018). This is rare for Juries, because size almost inevitably shrinks over time, and it demonstrates this Jury's commitment to supporting our understanding of shared decision-making. All participants engaged actively and enthusiastically at each session. Throughout, the Jury was empathetic to the challenges and pressures that healthcare professionals face on a daily basis. Their recommendations reflect their compassionate, pragmatic and reasoned participation.



Our Voice Citizens' Jury on Shared Decision-making
Health Report 1 February 2019



Box 4 - Our Voice Citizens' Jury on Shared Decision-Making

Erica Reid is Associate Director of Nursing and Allied Health Professionals in NHS Borders and Chair of the Citizens' Jury Oversight Panel

The purpose of the Our Voice programme is to engage the people of Scotland to improve health and social care. The Scottish Health Council was commissioned by the Chief Medical Officer to hold a Citizens' Jury on shared decision-making.

An Oversight Panel was formed to ensure a fair and rigorous process, agree questions, identify commentators and witnesses, monitor the process and advise on the Jury's findings. The Panel included representation from the public, clinicians, social work, an academic expert in public participation, Health and Social Care Alliance Scotland and the Royal Colleges of General Practitioners and Physicians.

The Citizens' Jury members were a stratified sample of the population, chosen by a 'near random' selection process to achieve as close to a representative sample of the Scottish population as possible. Over three sessions, the Jury deliberated the question: '*What should shared decision-making look like and what needs to be done for this to happen?*' Commentators, ranging from healthcare professionals to those who had experienced care, were selected to bring a range of perspectives to share with the Jury.

The Jury then developed 13 recommendations and prioritised them. The three main recommendations, as written in the Jury members' own words, are to have:

1. A programme to inform and educate patients of their right to ask questions of health professionals and which questions are useful to ask;
2. Training for all health and social care professionals on shared decision-making;
3. The opportunity for an independent person to join conversations between medical professionals and patients.

The Chief Medical Officer met with the Jury members in February 2019 and they shared their recommendations with her. The Scottish Government has committed to carefully consider each of the Jury's recommendations and reply to them all, either with a commitment to action or an explanation as to why that recommendation cannot be taken forward.



'My predominant experience is that patients and indeed citizens are appreciative of the challenges facing the NHS and that their requirements and hopes for the service are, in most cases, entirely reasonable. The vast majority are very understanding of the constraints and very grateful for the service that they have received. So it's an important and rewarding exercise to listen systematically to citizens and patients as it can provide a valuable reference point for how we can improve things.'

Peter Homa

The value of engaging our citizens is increasingly recognised. For example, following the introduction of the new GP contract in Scotland, the Scottish Government have begun to collaborate with stakeholders, including the Royal College of General Practitioners (Scotland) and the British Medical Association, to lead a national conversation to increase the public's understanding of the new models of primary care.

There may be no single 'best way' to engage with the public but we need a dialogue based on trust and mutual respect. In 2000, the House of Lords Science and Technology Committee produced a report calling for the rejection of what it termed the 'deficit model'.¹⁵ This is the notion that the gap between professional experts and the public is down to an information deficit that can be filled by expertise being provided to educate the public and, with this new information, the public would then be expected to agree with the professionals. This does not deliver good engagement. Professionals frequently discount or fail to understand the social and ethical values that the public bring to the discussion. Although the 'deficit model' argument was made in relation to science, it holds relevance for health and social care and for Realistic Medicine. It is far more productive for us to engage in a two way dialogue, to build trust and to understand the importance of the public's social values. The House of Lords report concluded that 'many of the issues currently treated by decision-makers as science issues may in fact involve many other factors besides science'. In the same way, we must accept that, to deliver Realistic Medicine, we need to consider many factors besides medicine.

FINDING THE TIME

'All interactions of care carry their own tempo and, in kind care, we give adequate time for this tempo to develop.'

Victor Montori

Lack of time to deliver a personalised approach to care is the barrier most frequently cited by professionals. This concern has some legitimacy: our health service has never felt busier and there are certain situations, particularly in the emergency setting, where it may not be desirable or possible to give more time to provide information and reach decisions. But are there ways of making better use of the time we have? Can we change the way we practise to create time?

Evidence suggests that, while lack of time can impede shared decision-making, the primary factors are often clinician attitudes and skills. Work by Rabinowitz indicates that, on average, doctors interrupt a patient's opening monologue after 12-18 seconds whereas, when left uninterrupted, patients typically speak for between 30 and 90 seconds, often disclosing significant concerns.¹⁶ Allowing these extra seconds may provide the clinician with valuable background for framing and personalising the rest of the conversation.

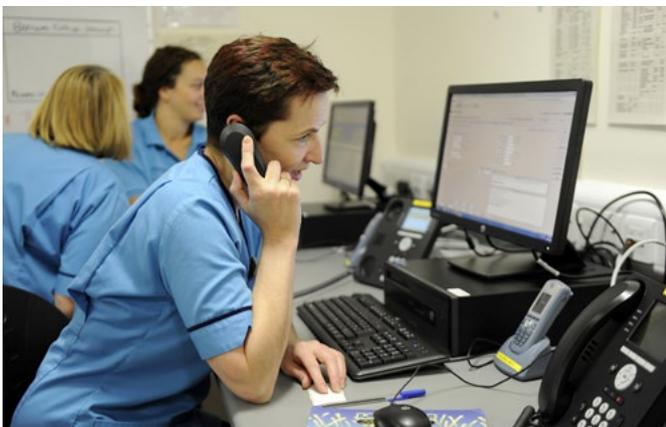


An initial investment of time can also save time downstream. Dr Al Mulley talks of there being two important diagnoses in a consultation – the medical diagnosis and the preference diagnosis.¹⁷ As a health service, we go to great lengths to avoid misdiagnosing the former and, if we do get it wrong, our response tends to be immediate and comprehensive. However, a misdiagnosis of a patient's preference tends not to be recognised, despite it having similar consequences for the patient.

By building a personalised approach to care, we reduce the risk of making this so-called 'silent misdiagnosis', leading to better understanding of people's needs, improved personal outcomes and ultimately time saved. Evidence of this can be seen by revisiting examples from Chapter 1. Two independent evaluations of the work of the Patient Experience and Anticipatory Care Plan Team (PACT) in NHS Lothian have found that PACT care plans are associated with a measurable reduction in acute hospital demand that outweighs the cost, both in time and money, of providing the service.

Likewise, in the year following the pilot of The Silver City Project in Aberdeen, emergency hospital admissions of people aged >75 (from that GP practice) fell by around 12% and outpatient referrals to Geriatric Medicine reduced from 10 to 4, allowing more effective use of Geriatrician time in contributing to Silver City multidisciplinary team (MDT) meetings.

Time can also be saved by making innovative changes to our services. This means rethinking which patients need to be seen, by when and by whom. Evidence from many specialities throughout Scotland has consistently demonstrated the benefit of promptly supplying patients with information leaflets regarding self-care, when to contact clinicians for advice and how to "opt-in" for a face-to-face review. This approach has been shown to reduce unnecessary outpatient attendances, freeing up resources for use elsewhere. Traditionally, no clinical information has been sought or provided for new outpatients until seen face-to-face, despite the accessibility of electronic patient records, laboratory results and imaging. If we can review this information at an earlier stage, certain outpatient appointments may not be necessary.



The Orthopaedic Team at Glasgow Royal Infirmary provide one such example. Traditionally, all non-operative limb fractures referred from Emergency

Departments to fracture clinics were seen face-to-face within 72 hours. A new model of care was introduced, based on provision of clinical information leaflets, an "opt-in" clinical helpline for patients and a "virtual clinic" where the Orthopaedic Consultant reviewed and triaged all new referrals. Now, less than 40% of patients require a face-to-face review but the right people are being seen at the right time. An evaluation of the service shows that 79% of patients are satisfied with the pathway, outcome and clinical helpline.

Other services have "made time" to deliver more personalised care by making better use of their whole clinical team. Box 5 shares the experience of the Breast Service in NHS Lanarkshire.

Similar approaches have been successful in primary care. Inverclyde are piloting the use of an Advanced Practice Physiotherapist (APP) as an alternative first point of patient contact within three GP practices, with a total patient list of 14,000.¹⁶ Reception staff at each practice were trained to offer patients APP appointments where appropriate. To date, the APP has provided over 1000 consultations, most of which would otherwise have been GP appointments. 94% of patients were seen once and did not need a further appointment with the physiotherapist. GPs are now able to use their time more effectively by focusing on patients more in need of their expertise. In qualitative evaluation, the pilot was rated highly by GPs, practice staff and patients, with patient feedback in particular being extremely positive.

**'Of all the work that's ever been done in GP practices, this has been the one that feels like it has truly taken work away. Patients are safer - there is quicker access to the most appropriate intervention because triage assessment conducted by the physiotherapist gets people to the right place sooner'.
GP, Greenock**

The service redesign proposed in *The 2018 General Medical Services Contract in Scotland* reflects the ambition to 'reduce and refocus' GP workload and use the wider primary care MDT to create more time for GPs to spend with patients most in need.¹⁸

These are all compelling examples of the unrecognised waste that exists in some of our care pathways and which consumes our time unnecessarily. Careful, thoughtful, design-led processes, such as those being

Box 5 - Breast Service Redesign in NHS Lanarkshire

Juliette Murray is a Consultant Breast Surgeon in NHS Lanarkshire

By 2012, there had been 4 retirements from a team of 6 Consultant Breast Surgeons working between the 3 acute hospitals in NHS Lanarkshire. In a challenging recruitment environment, we had to consider whether there were innovative ways of reconfiguring the service.

We trained a combination of sessional Specialty Doctors and Advanced Nurse Practitioners to see and assess patients. We designed a service footprint which matched capacity with demand and used team job planning with flexible sessions to promote cross-cover between colleagues, with the aim of keeping theatre sessions and clinics fully staffed and running 50 weeks per year. By having more than one subspecialty interest, staff are able to move between services based on demand. We concentrated on role extension: trained Consultant Radiographers to do most of the work of a Breast Radiologist; Surgical Care Practitioners to perform minor surgical procedures; Clinical Support Workers to become scrub practitioners.

We have worked hard to match capacity within the service to demand. We now have a 10-14 day wait for all urgent and routine referrals to the breast service across Lanarkshire and a less than 2 weeks wait for surgery. We have focused on all parts of the pathway, from working with local GPs to develop referral pathways to considering which benign surgical procedures we should perform. We have developed virtual clinics for family history patients and moved to a patient-led follow-up model for breast cancer follow-up, with a 70% reduction in patients needing to attend these clinics. This allows staff to spend more time with those patients who have more complex needs, which leads to higher patient and staff satisfaction.

Having long-term committed staff means that trainee surgeons who come to work with our team are supernumerary and their training time can be prioritised. They are able to spend 2-3 days per week in theatre and we can offer dedicated training clinics.

By creating a little flexibility in our system, we have been able to offer both surgical and radiological support to the Breast Units of neighbouring Health Boards, in Fife, Dumfries and Galloway and Forth Valley.

undertaken through the Waiting Times Improvement Plan and by the Scottish Access Collaborative, can help us to improve how we use this most precious resource.

Processes include a systematic way of spreading enhanced practice roles when they have been shown to work elsewhere and accelerating the implementation of successful team service planning models, such as the one described in Box 5.

Supporting professionals to seek out and eliminate unwarranted variation and to practise shared decision-making will help us to tackle over-treatment. This will not only reduce harm and waste in our system but also has the potential to increase capacity by redirecting those resources currently used for interventions of limited, or no, clinical value to more appropriate care. This, in turn, will have a positive impact on waiting lists.

CONCLUSION

It is true that challenges must be overcome to deliver a more personalised approach to care. However, if we are courageous in committing to our 2025 vision, I firmly believe that Realistic Medicine will enable us to succeed. A more personalised approach towards our patients and our citizens can foster their engagement, allowing us to understand and co-create the care they really value. Giving time to patients can often save time for professionals, and the appropriate redistribution of work - using all the assets of our diverse teams - can improve patient care, rather than undermine it.

CHAPTER 3

SUPPORTING OUR WORKFORCE TO DELIVER PERSONALISED CARE

So far, my report has focused on our patients – their needs, preferences, expectations and values. However, to successfully build a personalised approach to care, we must not lose sight of the fact that our workforce, our most valuable asset, are also people and we need to look after them too.

SUPPORTED WORKFORCE

**'You cannot give what you do not have'.
Maureen Bisognano**

It is rightly a matter of concern that staff working in the NHS are subject to high levels of stress and strain resulting in ill-health and absenteeism. This also impacts on financial costs and, importantly, on patient care. Many of the findings presented in the General Medical Council's (GMC) 2018 report *'The state of medical education and practice in the UK'* make for uncomfortable reading.¹⁹ 60% of doctors surveyed across the whole of the UK reported that their satisfaction with their work-life balance had deteriorated (either somewhat or significantly) in the past 2 years, with only a fifth reporting an improvement. 3/10 doctors felt unsupported by management or senior colleagues at least once a week. 1 out of 4 doctors said they had considered leaving the medical profession at least every month. The report concluded that the medical profession is 'at a critical juncture'. Similar challenges face non-medical healthcare professions.

**'Healthcare is a caring and learning system. It is not driven by data, industrial processes or technology. It is driven by people. It is not systems responding to people but people responding to people. The systems, technology and information are back-up to support people. But the people are first. And if people are dissatisfied, burnt out, confused about what their role should be, unable to work together in teams and unable to communicate, and if people are not surrounded by a culture of safety and gratitude, a culture that recognises their work, a culture that allows them to feel proud of what they can achieve, they will be spent. And if you put those people on the front-line, they will be your final common pathway, your bottleneck in your ability to care in a careful and kind way'.
Victor Montori**

An effective and sustainable health and care system focuses on meeting the health and wellbeing needs

of everyone in that system – patients, carers and staff alike. This is the so-called ethic of reciprocity – making the care you give the care that you yourself would want to receive.²⁰ It is recognition that the health service must care for its staff in order for them to provide the best care to those they serve.

**'Staff often achieve extraordinary results in spite of organisational systems rather than because of them'.
Peter Homa**

Peter Homa is a former Chief Executive of Nottingham University Hospitals NHS Trust and is the foundation chair of the NHS Leadership Academy. Throughout his career, he has championed the wellbeing of the health workforce. Peter contends that, while there is first and foremost a moral duty for us to look after staff in the best way possible, it is also the case that staff do great work when they feel supported, confident, appropriately challenged and part of an organisation with core values with which they identify. Furthermore, organisations must ensure that staff from all backgrounds have a strong sense of inclusivity so that, over time, those that serve the population increasingly reflect its diversity.

When considering how best to support the workforce, we should perhaps reflect on two-factor theory, postulated in the 1950s by the American psychologist Frederick Herzberg.²¹ The work emerged from Herzberg's interviews with employees in engineering and accountancy about what pleased and displeased them about their work. Sources of pleasure (termed motivators) included the work itself, professional responsibility, achievement, recognition and opportunities for advancement. Dissatisfaction was determined by so-called hygiene or maintenance factors, such as the work conditions, a person's relationship with their peers and seniors, and the presence or absence of a culture of dignity and respect. Interestingly, Herzberg found that the factors leading to job satisfaction were separate and distinct from those that led to job dissatisfaction. In practice, this means that job satisfaction cannot be achieved simply by remedying the causes of job dissatisfaction and, similarly, job dissatisfaction cannot be eliminated simply by adding those factors known to create job

satisfaction. Instead, there needs to be a dual approach, an understanding that the greatest improvements for staff are achieved when both sides of the coin are examined.

Almost certainly, there are fundamental motivational differences between the employees interviewed by Herzberg and the staff who work in the vocational professions of health and care. However, as a conceptual framework for improving the wellbeing of our workforce, Herzberg's theory holds value to this day.

In *Practising Realistic Medicine*, I considered some of the ways in which Scotland is addressing those hygiene factors that lead to job dissatisfaction: the Professional Compliance Analysis Tool (PCAT) to improve working patterns and achieve intelligent rota design; the decision agreed between Scottish Government, NHS Boards and British Medical Association (BMA) Scotland's Scottish Junior Doctors Committee that, from August 2019, the rotas of all junior doctors will include mandatory 46 hour recovery periods after runs of night shifts; and the *Let's Remove It* campaign launched by the Royal College of Surgeons of Edinburgh to tackle cultures of bullying, undermining and harassment in healthcare.²²

Further progress has been made since my last report. The Health and Care (Staffing) (Scotland) Bill was introduced to Parliament in May 2018. Its general principles were unanimously agreed in December 2018 and stage 2 of the process was completed in February 2019. The legislation seeks to ensure safe, high quality services, creating better outcomes for patients and improving the wellbeing of staff.²³ The Bill will support the professional-led development of evidence-based approaches to workload planning and will encourage an open and honest culture where staff are engaged in discussions around staffing requirements and feel safe to raise concerns.

Following the GMC 2018 report, there is now a UK-wide review of medical students' and doctors' wellbeing, led by Professor Michael West and Dame Denise Coia. Dame Denise is also co-chairing the Scottish Advisory Group on the Wellbeing of the Medical Profession, established in August 2018 by the GMC and NHS Education for Scotland, and attended by stakeholders from the NHS, BMA, GMC, Royal Colleges and Scottish Government.

We should also be proud to acknowledge our successes. In their most recent national review of Scotland Deanery, the GMC identified many

areas that are 'working well', defined as not only meeting GMC standards but well embedded across our organisations.²⁴ These included supportive departmental cultures and the ready availability of pastoral support. There were no concerns identified over bullying or undermining. We are also gauging staff wellbeing through staff governance monitoring processes in every health board and the iMatter Staff Experience Continuous Improvement Model. Evidence from the first national report suggest that the model is having a positive impact.²⁵

We should also direct our focus towards motivators, those factors that lead to job satisfaction. We must allow our staff to find what the Institute for Healthcare Improvement (IHI) describes as 'joy in work', the feeling of success and fulfilment that results from meaningful work. Just as health is more than the absence of disease, so too joy is more than the absence of burnout.²⁶

In Peter Homa's experience, some of this can be achieved by leaders connecting with staff, providing them with formal and informal opportunities to share their sources of fulfilment and frustration in their role and designing services based around them:



'Many of our hospital systems are designed around the convenience of the organisation. Listening to patients and to staff provides a hugely important and valuable opportunity for redesigning services in a way that makes much better use of patient time and staff time while improving the experience for both.'

In Chapter 1, we considered the importance of asking patients 'what matters to you?', but we must also ask the same question of our staff. Just under half of doctors (49%) surveyed by the GMC believe the time available to reflect on their practice has decreased, with only 16% saying it has increased.¹⁹

Finally, we must find space in our system for approaches that address both sides of Herzberg's model. A good approach is to introduce Schwartz Rounds. The connection between supported staff and positive patient experience has been at the heart of the Schwartz model from its inception. Kenneth

Schwartz, after whom the Rounds are named, died in 1995 from lung cancer. During the course of his treatment, he wrote about the way that healthcare professionals, while unable to cure his disease, made his plight more bearable by attending to the so-called 'small' things that matter to people. After his death, the Schwartz Center for Compassionate Healthcare in Boston, USA, developed and evolved the Rounds model. The Point of Care Foundation introduced Schwartz Rounds to the UK, and continues to train facilitators and support organisations to establish Schwartz Rounds programmes. Box 6 explores this in more detail.



Box 6 - Schwartz Rounds

Jocelyn Cornwell is Chief Executive of The Point of Care Foundation and is credited with bringing Schwartz Rounds to the UK

A Schwartz Round is a multi-disciplinary forum for clinicians and support staff at all levels to reflect on their work in healthcare and its psycho-social and emotional impacts. The aim of Rounds is to strengthen relationships with patients, build empathy and compassion across organisations and provide staff with a safe psychological space in which they can talk to each other about all aspects of their work.

It is hard to communicate exactly what makes a Schwartz Round different from other meetings, but how they work is simple. They take place each month, usually at lunchtime with a snack provided, and last one hour. They require expert facilitation by a facilitator and clinical lead appointed from within the organisation and trained by The Point of Care Foundation.

The numbers who attend Rounds vary between organisations: in large hospitals, audiences can be as big as 150-200; in small and more dispersed organisations, they average 30-40.

At the beginning of a Round, the facilitators remind people about the ground rules. Rounds are only for staff and allow a confidential space for reflection. During the Round, everyone in the room is equal. A 'panel' of three people briefly introduce a story about a patient or an experience at work that is connected to a pre-agreed theme. The facilitators then invite the audience to ask questions, comment and reflect. A Schwartz Round is not a debrief or a place for decision-making or teaching. Often, there are short periods of silence. Invariably, there is a remarkable level of active listening and attention.

The simplicity of the model belies its impact and effectiveness. Evidence shows that people who attend Rounds regularly are half as likely to suffer psychological distress as their non-attending colleagues, and that participating in Rounds, even for people who never speak, reduces isolation, makes them feel more connected to colleagues and puts them back in touch with the motives that brought them to healthcare in the first place.²⁷

'Powerful and emotional. You do forget that other colleagues feel the same as you.'

Paul Graham is Head of Spiritual Care and Wellbeing in NHS Lanarkshire and was one of the first trained facilitators of Schwartz Rounds in NHS Scotland

The first ever Schwartz Round I attended was in spring of 2013 at the Golden Jubilee National Hospital, where it became a regular feature in the Hospital's calendar for staff. In University Hospital Hairmyres, we identified a core group of colleagues from across disciplines who would become trained facilitators and would plan and organise a programme of Schwartz Rounds each year.

'It's important that we get staff off the wards to attend events like this. It's for their wellbeing as they are faced with these scenarios and stories every day'.

We have heard a variety of themes discussed at the rounds: "A patient I'll never forget", "When things go wrong", "What happens when you can do no more?", "When the unthinkable happens!", "Can we be friends with our patients?"

As a trained facilitator, it is essential that we create and hold a safe, confidential space for colleagues to share their experiences. People are often surprised by the emotions they experience when re-telling their story. Although it can be overwhelming to realise that we carry so much 'emotional residue' from our previous encounters, it can also be very helpful to hear that we're not on our own and that it's OK to feel the way we do. That's why we allow time at the end of a Round for people to chat before going back to their workplace.



Hospitality and welcome is an important aspect of Rounds so we always start with some food. There is something simple and profound that happens when we eat together: we create a place for building relationships and trust and for establishing community across professional and hierarchical boundaries. The dynamic in an organisation changes significantly when you hear a Chief Executive speaking about a patient he'll never forget, a Medical Director recounting an

experience that has stayed with her for over thirty years, or a Nurse Director describing the impact on her of a poor outcome for a patient and their family. People often comment that, if you've heard someone share a story at a Schwartz Round, it becomes easier to contact them in day to day work.

Hearing about the impact of events on our colleagues opens our understanding of the personal toll of working in healthcare. Who would have thought that the death of a patient would impact colleagues working in departments which may not have been considered 'front-line'? I

'Glad to know that I'm not alone in trying to walk in other people's shoes, and walk their path along with them in support'.

remember a situation where the kitchen staff realised that the name of a long-term patient was no longer on their list for special meals. On finding out that the patient had died, they held a minute's silence in respect. Likewise, what is the impact on colleagues working in our laboratories when preparing test results that can only indicate a very poor prognosis? The Schwartz Round is the safe forum for discussing and reflecting on these challenges.

COMPASSIONATE LEADERS

A supported workforce in isolation is not enough. We also need strong clinical leadership to ensure that the norms and values of our NHS reflect its core purpose and its workforce's values. When the NHS was founded in 1948, its core work value was compassion, to serve a society still deeply traumatised in the aftermath of war. 70 years later, compassion continues to fuel those working for the NHS. We therefore need leaders at every level in every NHS organisation in Scotland to embody compassion.

Professor Michael West is a Professor of Organisational Psychology at Lancaster University Management School and an expert on leadership within the health service. He is also co-chair of a UK-wide review of medical students' and doctors' wellbeing. Professor West's vision of 'compassionate leadership' is one that we must adopt in order to support our workforce to deliver Realistic Medicine. He argues that it is not difficult but it relies on four behaviours:

- **Attending** – paying attention to staff and 'listening to them with fascination';
- **Understanding** – talking with staff to understand better the challenges they face in delivering care;
- **Empathising** – displaying empathy to staff, particularly as we know that between 30% to 40% are experiencing chronic stress;
- **Helping** – maintaining a focus on helping staff to do their jobs effectively.

For many years, research has demonstrated that these four behaviours are fundamental to effective leadership, with listening being the most important skill for a leader and helping being the most important task.^{28,29} Compassionate leadership ensures high levels of staff engagement, a key factor in strong health service performance, care quality and patient satisfaction. In turn, there is more quality improvement and innovation and better relationships between all groups involved in the delivery of health and care.

Peter Homa echoes Michael West's sentiments by talking of 'compressing the distance between board and ward'. We need to make sure that board members and other senior leaders are not satisfied simply with attempting to understand their organisations through written reports. Instead, they must triangulate this by investing time in visiting and listening to staff in their workplaces.

Patient safety conversations are a particularly potent mechanism for understanding the challenges that staff face. Simple but open questions can unlock a wealth of vital information – How safe is this ward or department? What was the last harm event? What do you think the next harm event will be? What might we do to avoid it? By listening to staff and valuing what they say, everyone finds greater meaning in their work and, importantly, patient care improves.



CULTURE OF STEWARDSHIP

'A good steward leaves the farm in a better condition than they found it.'

Muir Gray

To build a more personalised approach to care today, we need the three components I have discussed already: engaged patients, a supported workforce, and compassionate leaders. However, to deliver Realistic Medicine into the future, a fourth component is also required. It's what Muir Gray calls the 'culture of stewardship'.³⁰

Stewardship refers to holding something in trust for another generation. We must recognise that we are responsible not only for the health service of today but also for the health service of tomorrow. This means making good decisions that focus on delivering better value care and creating a culture that will deliver a sustainable health and care system for decades to

come. For parts of our Realistic Medicine vision, this can be thought of as prioritising those things that add value. For the principle of personalised care, this means placing the patient at the centre of our health and care system whilst also recognising that our workforce is our most valuable asset and needs to be supported now and in the future.

CONCLUSION

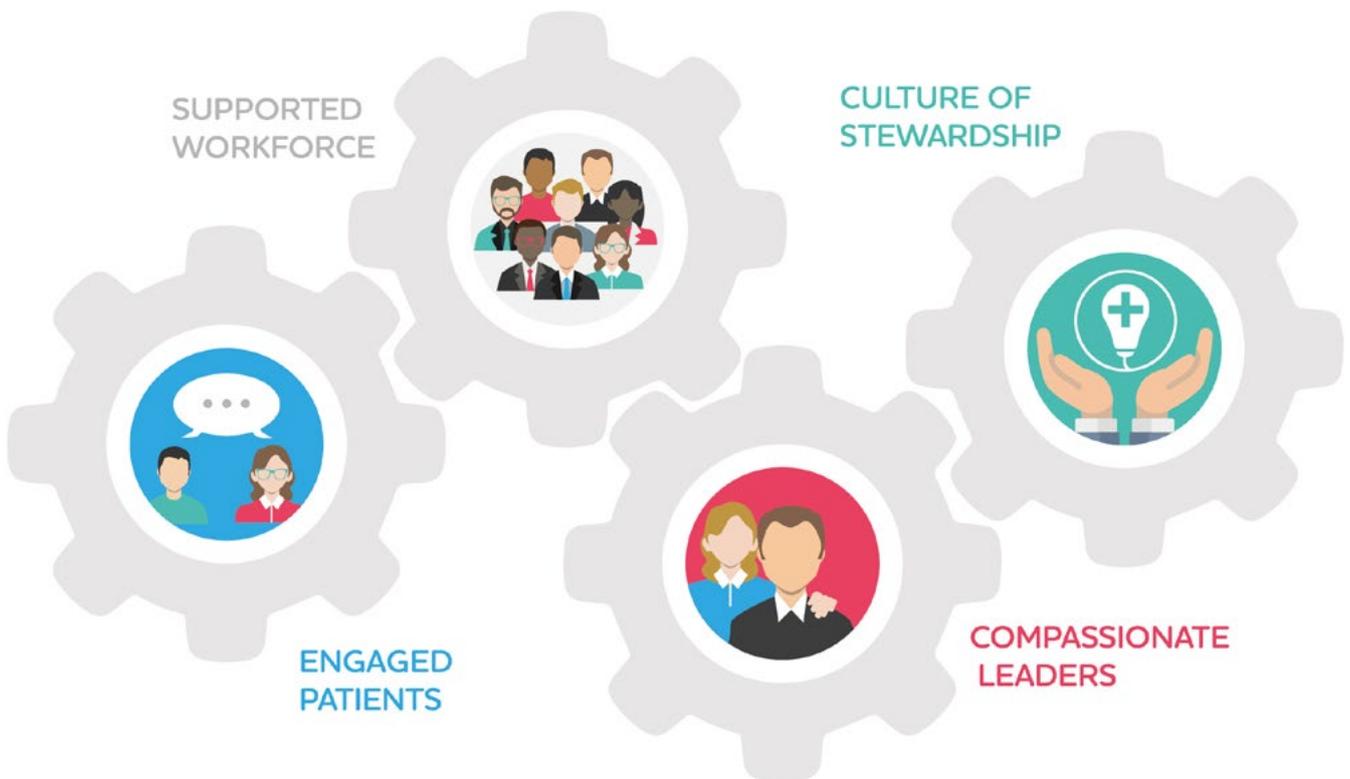
Creating environments where staff feel valued, respected and supported is vital if we are to retain and develop our workforce to respond to the challenges of delivering a world class health and care service for the people of Scotland. To do this, we must properly understand the challenges faced by our staff and we must support them with effective, compassionate leadership at all levels and in all places. Our call to develop a culture of stewardship is not just about how we create clinical value for our patients, but also about how we value and sustain the very people who provide this care every day. Peter Homa is frank in his assessment of the challenge ahead:

'the question is not if the opportunities for improvement exist but if we choose to take them'.

By practising Realistic Medicine, we can make it the latter.



CULTURE OF STEWARDSHIP



CHAPTER 4

PERSONALISING REALISTIC MEDICINE ACROSS OUR PRINCIPLES

My report has explored the ways in which we can build a personalised approach to care – both for our patients and for our workforce. But, to deliver our 2025 vision, we need to go further and consider the other Realistic Medicine principles too. In this chapter, we explore the synergies between each principle and the personalised approach to care.

CHANGING OUR STYLE TO SHARED DECISION-MAKING

Of all principles, shared decision-making is the one with the most obvious links to building a personalised approach to care. Put simply, it is hard to conceive of how one could be achieved without investing time and skills in developing the other. In 2018, the Scottish Government conducted a mixed-methods study investigating good practice in shared decision-making and consent.³¹ The work consisted of 3 phases: a literature review on current policy and guidance; a group consultation with the Person-Centred Stakeholder Group; and an online survey for NHS Board Medical Directors and Clinical Governance Leads. The key finding was that all healthcare professionals should adopt a personalised approach within their practice. The report's main recommendation was to 'bring the conversation back to the room' – to allow a rich and meaningful dialogue built on partnership and placed at the heart of every interaction between those giving and receiving care. The study suggests that we:

- Provide more guidance on effective ways of communication to enable health professionals to clearly explain risks, benefits, outcomes and alternative treatments;
- Develop a national standardised repository of validated evidence-based information about treatments and procedures and the associated risks;
- Provide clear guidance on the appropriate use of, and better access to, high quality decision-making aids for healthcare professionals and patients;
- Provide staff with education and adequate skills to communicate information clearly to the patient and ensure the patient has understood it ('teach-back' technique); and,
- Provide staff with training on how to build a more supportive relationship with the patient to enhance person-centred consultations.

It is interesting to reflect on how closely several of these findings match the recommendations of the Citizens' Jury (Chapter 2), and we must act on them.¹⁴ In January 2019, with support from the Scottish Government, NHS Education for Scotland appointed a lead for Realistic Medicine. Their role will be critical in supporting training programmes on shared decision-making and value-based healthcare to help us practise Realistic Medicine and deliver more personalised care. As part of this work, we will also promote training and resources that exist already, such as Effective Communication for Healthcare (EC4H) workshops, available in many NHS Boards.³² These communication workshops have been designed for a range of different professionals and cover topics including anticipatory care planning, shared decision-making and challenging communication scenarios.



REDUCING HARM AND WASTE

'Personalised healthcare and population healthcare are two sides of the same coin'. Muir Gray

Realistic Medicine is responding to the twin threats of harm and waste in healthcare by focusing on the concept of value. In *Realising Realistic Medicine*, I explored the relationship between value for a population and value for an individual using this graph from Muir Gray (see Figure 1).²

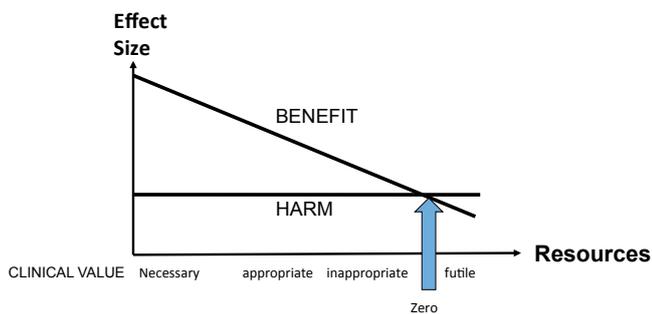


Figure 1: Donabedian-style graph of the relationship at an individual level between healthcare benefits and harms, and increasing resources

It shows that, when there is only enough resource to make interventions available to a few, they are offered to people who have most to gain and who are more willing to accept risk – in these circumstances, it is more likely that we are delivering high value healthcare. However, as investment increases, interventions are offered to people who are less severely affected, so the maximum benefit that this person can expect is less but the probability and magnitude of harm remains the same. This can produce low or even negative value healthcare. By building a personalised approach to care, we are better placed not only to communicate these concepts to our patients, but also to understand what benefit and risk means in the specific context of their lives.

A personalised approach to care can reduce harm in other ways too. An adverse event is a situation where a person experiences an outcome of treatment or care that is unexpected and unwelcome. There can be lasting psychological and emotional consequences for those affected directly and for the staff involved. In Scotland, *Being Open* provides a best practice framework for all healthcare organisations in such a situation.³³ It creates an environment where patients and their families feel supported and where healthcare professionals and managers have the confidence to act appropriately. Psychological harm to families following an adverse event is reduced when they experience compassionate care, when their perspective on the event is valued and when they are central to the review of care.

'I think patients and families find it very positive, which is bizarre when it can be something very negative that's happened to them. But from my experience, they don't expect you to be so honest and open with them and when you are, I think they truly value that, and I think they trust you more because they feel you're not hiding anything from them'.

Midwife trained in Being Open

'The best endorsement is we have come out the other side happily...we were so well supported. The lasting benefit is that I don't really think about it at all now...'

Parent receiving Being Open care

Future harm is reduced when staff engage with the learning and improvement generated from the adverse event review reports. In maternity services in NHS Lothian, staff realised that families were not being involved consistently in the reviews of care that followed adverse events. With *Being Open*, staff have worked to overcome barriers in communication with families, so that they are able to engage soon after an event in an open and transparent manner and elicit their concerns effectively. These concerns are then incorporated into the review and families are supported as feedback is shared from the review report. Families now report greater trust and confidence in the service and the NHS Board. Staff feel more confident about building relationships with the families and more confident about being able to provide personalised care.



TACKLING UNWARRANTED VARIATION IN PRACTICE AND OUTCOMES

Variation in healthcare exists because health systems are complex and the population has differing needs. Unwarranted variation is variation in healthcare that cannot be explained by need, or by explicit patient or population preferences.³⁴ Persistent unwarranted variation is of concern because it affects health and social care funding, equity of access to healthcare, and can cause hidden harm. Identifying and addressing this is essential to improving outcomes and to delivering Realistic Medicine.

In earlier Realistic Medicine reports, I outlined our plans to support clinicians to tackle unwarranted variation through our Value-Based Healthcare (VBH) work program. Over the past year we have made great progress, appointing Realistic Medicine Clinical and Finance Leads across Scotland, training them and 120 others in the principles of VBH and awarding funding to support 11 VBH improvement projects. In September 2018, we published the beginnings of a Scottish Atlas of Healthcare Variation and have added new maps on a regular basis, with plans for continued expansion in the months and years to come.³⁵ The Atlas is publically available and highlights geographical variation in the provision of health and care services and associated health outcomes across Scotland. Each map is accompanied by an explanatory narrative to support public understanding and interpretation of the Atlas. Box 7 displays our Atlas map for cholecystectomy (surgical removal of the gallbladder).

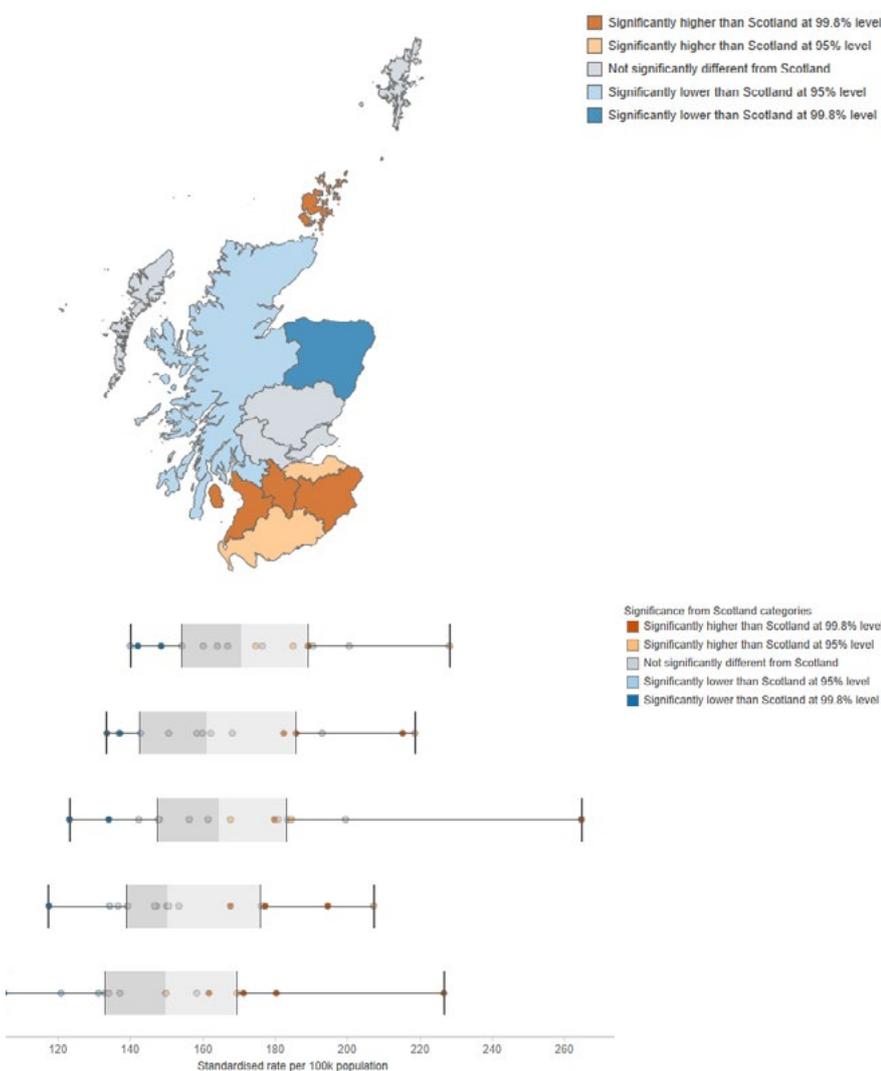
As discussed in *Realising Realistic Medicine*, the Atlas does not set out to explain this variation or provide a measure of performance. It does not say what the 'correct' rate of a procedure or treatment is or indicate that high or low is bad and average is ideal. Instead, it is a tool which provides informative and easily accessible data to allow clinical teams to question, debate and explore the variations demonstrated, and use these conversations to promote quality improvement. It is hoped that the Atlas will help to identify over- and under-treatment across Scotland and support healthcare teams to generate solutions to reduce waste and harm.

Box 7 - How to use the Scottish Atlas of Healthcare Variation

Prior to publication, we tested the Atlas with healthcare professionals, the public and policy makers. We used their feedback to refine and improve the Atlas, and continue to encourage users to let us know how they are using the Atlas and how we can make it better. Information Services Division (ISD) Scotland have created several user guides, videos and Frequently Asked Questions to assist clinicians in understanding and interpreting the data, and will be hosting Webex training sessions to increase understanding.

The Atlas is interactive. It allows the user to choose how to display the data and gives a demonstration of geographical variation and variation over time.

The images below demonstrate rates of cholecystectomy across Scotland:



Maps - the map highlights each NHS Board in a colour indicating how significantly different the standardised rate is from the Scotland value, and in which direction. Significance is based on whether the Scotland value falls within the confidence interval of the value for the NHS Board, at two confidence levels: 95% and 99.8%.

Boxplots - the boxplots show the standardised rates for NHS Boards in sequence from lowest to highest, for each financial year. A central 'box' indicates the inter-quartile range: that is, it extends from the 25th to the 75th percentiles (the middle 50% of data values), with the median indicated by a line. The 'whiskers' extend out to the minimum and maximum values. The fold-value is also shown under the financial year to allow quick comparison across the time period.

While there may be less overlap between tackling unwarranted variation at a population level and building a personalised approach to care, the two principles are not mutually exclusive. The Specialist Palliative Care Service in NHS Fife has developed an innovative model of best supportive care aligned to both principles.³⁶ The catalyst for change in Fife was the recognition by staff that many patients with advanced lung cancer were in their last weeks of life at diagnosis, with only a small window to benefit from best supportive care (i.e. palliative care when anti-cancer treatment is not possible). Some patients were receiving high quality care delivered by a range of professionals, often in primary care, but others received little or no support.

This variation in experience was not accounted for by difference in need. Instead, it reflected variation in the system, with professionals describing ad hoc referral routes, lack of clarity around roles, inconsistent follow-up and suboptimal communication. The new model of care has tackled that unwarranted variation by ensuring that patients are consistently identified and all receive a personalised approach to care, including prompt multidisciplinary assessment, support and follow-up in a location that suits the person's needs and preferences. Through shared decision-making, patients are supported to pursue only the follow-up that is likely to be of benefit. Routine hospital appointments, when deemed no longer necessary, are cancelled. Information about patient wishes is shared reliably across the health system. Feedback from patients, carers and staff has been overwhelmingly positive.

'If somebody had explained to us, not necessarily what was going to happen, but what was available to us. You just felt... "into the abyss".'

A patient before NHS Fife's new model of best supportive care

'Everything they said they would put in place happened'.

A patient receiving NHS Fife's new model of best supportive care



**TACKLE UNWARRANTED
VARIATION IN PRACTICE
AND OUTCOMES**

MANAGING RISK BETTER

Health and social care professionals are increasingly aware of the need to manage risk effectively but, for many, this can lead them to practise defensive rather than Realistic Medicine. In previous reports, we have discussed how communication failures are a common theme in most complaints, particularly those around consent. It is not just lack of communication but the nature, frequency and content of it. By building a personalised approach to care, we reduce this risk. We become more transparent in our conversations, more open and meaningful in our dialogue about the risks and benefits of different courses of action, and more aware of what matters most to the person. This leads to less criticism and fewer complaints rather than more.

'One of our roles as professionals is to be leaders in openness and I include when things go wrong, as well as when things go well. When facing dilemmas, we must acknowledge them to the public that we serve, rather than try to overly finesse the information.'

Peter Homa

Adopting a personalised approach can also help us to manage risk at a system level. Human Factors and Ergonomics (HFE) is the scientific discipline concerned with understanding and improving the 'fit' between people and their working environment to ensure a safer, more productive and efficient workplace. It is about designing for people and supporting our workforce. Scotland is well-recognised internationally for its success in many fields of interest to HFE, such as non-technical skills training for surgeons and anaesthetists, clinical skills and simulation, the Scottish Patient Safety Programme, team working initiatives, safety culture assessment, significant event analysis and safety checklist design in primary care.

But substantial work still needs to be done in spreading and normalising HFE thinking and practices. Over the past two years, NHS Education for Scotland and the Royal College of Surgeons of Edinburgh have co-led ongoing national development work to plan how best to integrate HFE into everyday health and care delivery. The goal is to embed these concepts as seamlessly and successfully as in other safety-critical industries, such as energy and transport – sectors which are significantly less complex and risky than healthcare but paradoxically attract considerably more HFE-related attention. Working in partnership with over 150 colleagues from NHS Boards, universities and

professional bodies, they have identified priority areas where HFE can potentially add value to existing efforts to improve care system performance (e.g. care safety, productivity, efficiency, reliability) and workforce wellbeing (e.g. health and safety, patient experience, staff welfare, work enjoyment). In this sense, valuing the person (patient or staff) is both the input and the output of the HFE process.



BECOMING IMPROVERS AND INNOVATORS IN HEALTHCARE

'A desk is a dangerous place from which to view the world.'

John Le Carré

For our vision of Realistic Medicine to be realised, professionals need to feel empowered to embed its principles in to those parts of the system that they best understand. This requires each person to be at the forefront of improvement and innovation in their local area. To lead the change rather than be led.

Effective improvement and innovation is all about people. In his seminal work on quality management, Joseph Juran emphasises the importance of quality planning and understanding needs and assets from the customer's perspective when setting priorities for improvement.³⁷ He also highlights the value of building relationships and supporting individuals to become equal partners in co-producing services. These principles have such strong relevance for health and social care that aspects of Juran's quality framework have been adopted for use by Healthcare Improvement Scotland.³⁸

It has been said that 'people ignore design that ignores people' so, when making improvements to the way we

deliver healthcare, we must always engage with our patients, their families and our staff.³⁹

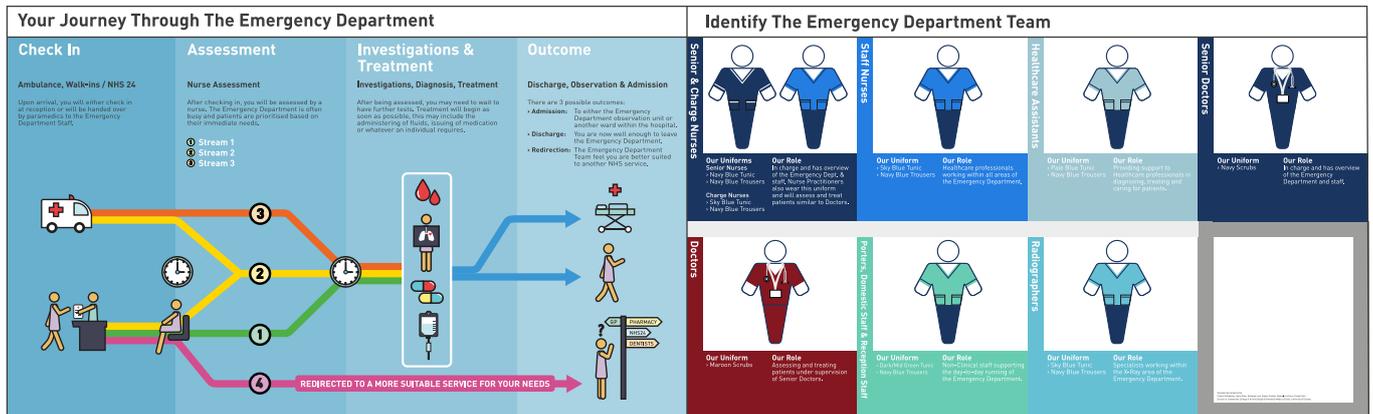
A fantastic example of where this approach has been successful is in the redesign of the Emergency Department (ED) in Ninewells Hospital, NHS Tayside. Here, NHS staff, local medical students and design students from Duncan Jordanstone College of Art and Design at the University of Dundee collaborated with patients and families to improve people's overall experience of the ED. The medical students shadowed patients through their journey and gathered information by questionnaire. Most people were very satisfied with their experience but were keen for more information about how long they would wait, who they would see and what might happen after they were seen.

The students then worked with colleagues in interior, graphic and product design to produce wall art that illustrated the process (see Figure 2). Patients were able to use this to follow the standard journey through the ED and learn more about the roles and responsibilities of staff wearing each type of uniform. Patient information cards were created to explain why there might be delays in being seen. These prototypes were then tested.

Before the introduction of these cards, 1 in 5 patients could identify different members of staff and their roles and 60% felt they knew why they were waiting and what the next step in their journey would be. After the design work, all patients were able to answer these questions. The department has now been redecorated accordingly.



Figure 2: New Wall Art for Emergency Department in Ninewells Hospital, NHS Tayside



CONCLUSION

I very much hope that my report has demonstrated that, while the principles of Realistic Medicine are presented visually as distinct entities, they are, in practice, inter-related and inter-dependent. I also hope that it is clear that building a personalised approach to care is the running motif throughout our Realistic Medicine vision and our most important objective.

In our first report in 2016, I asked 'can we' achieve these principles. Having witnessed the fantastic progress that's been made over the last 3 years, it is clearly now time for this to change. I am convinced that, together, 'we can' build a personalised approach to care. And I believe wholeheartedly that **we can** deliver Realistic Medicine.

REALISTIC MEDICINE

WE CAN:

- CHANGE OUR STYLE TO SHARED DECISION-MAKING** (Icon: Two people talking)
- BUILD A PERSONALISED APPROACH TO CARE** (Icon: Network of healthcare professionals)
- REDUCE HARM AND WASTE** (Icon: Radiation symbol with a slash and a pill bottle)
- TACKLE UNWARRANTED VARIATION IN PRACTICE AND OUTCOMES** (Icon: Six syringes)
- MANAGE RISK BETTER** (Icon: Scales of justice)
- BECOME IMPROVERS AND INNOVATORS** (Icon: Three lightbulbs)



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APPENDIX 1

REALISTIC MEDICINE SURVEY 2018

In 2016, I wrote my first Annual Report recognising that current models of healthcare do not always suit the aspirations of the workforce and need to change. The six principles of Realistic Medicine emerged through my conversations with staff about how they wanted to practise healthcare. In the three years since then, I have continued these essential conversations and have received a wealth of staff feedback in person and through letters, emails and social media. All of this has been invaluable in informing the Realistic Medicine agenda.

Our shared vision for Scotland is that all health and care professionals will be practising Realistic Medicine by 2025 and how we achieve it will continue to be shaped and delivered by our workforce. Last year, I decided to ask people working across health and care for their views on where we need to focus our efforts to support people to practise Realistic Medicine. In October 2018, a survey was conducted to explore staff views on Realistic Medicine: its concept; its impact to date; the perceived barriers to its successful delivery; and priority areas for where it should go next. The survey was distributed widely across Scotland: to NHS Board Chief Executives and Directors of Medicine, Nursing, Pharmacy, Public Health and Finance; as well as Chief Officers of Integration Authorities – with a request for the survey to be shared with all of their staff.

SURVEY POPULATION

In just 3 weeks, a total of 2,464 responses were received. 51% of respondents were doctors, 15% were nurses, 13% were Allied Health Professionals and 11% were pharmacists. The remainder of respondents were dentists, healthcare service managers, finance staff and those working in the ambulance service.

CONCEPT OF REALISTIC MEDICINE

Ninety five percent of respondents fully or somewhat agreed that the principles of Realistic Medicine matched their own personal beliefs and values about how healthcare should be practised in Scotland. Only 5% felt that there was little or no alignment with their own ideals.

IMPACT OF REALISTIC MEDICINE

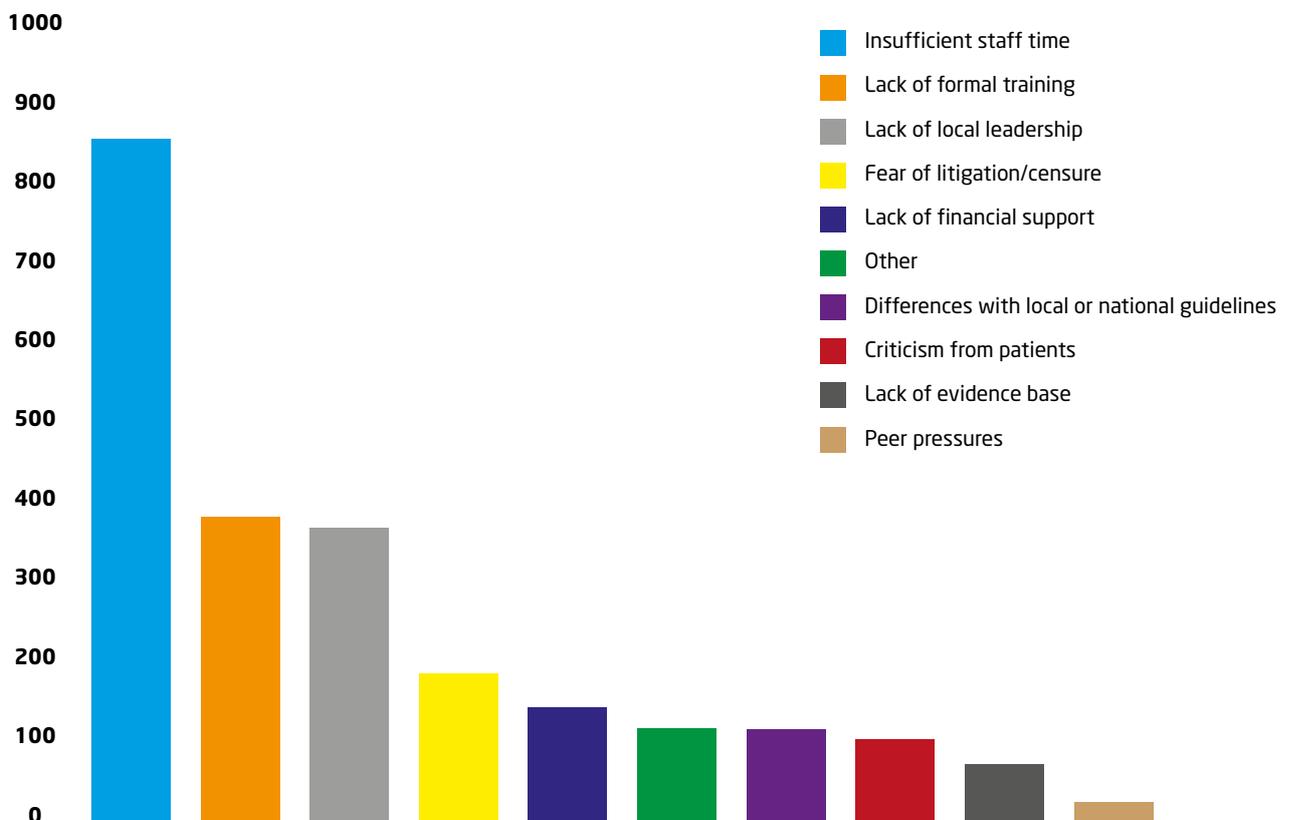
When considering the extent to which Realistic Medicine has influenced the practice of healthcare in Scotland over the last 3 years, 61% of respondents felt that it had had a positive influence, with 37% believing that Realistic Medicine was yet to have a meaningful influence.

BARRIERS FOR REALISTIC MEDICINE

People were also asked to consider the barriers to practising Realistic Medicine (Figure 1). The three biggest barriers they identified were:

- insufficient staff time (36%);
- lack of formal training (16%); and,
- lack of local leadership (16%).

Figure 1: Greatest barriers to making changes and improvements aligned to Realistic Medicine [base: 2388 respondents selected their biggest barrier]



FUTURE OF REALISTIC MEDICINE

People were also invited to prioritise the importance of each of the Realistic Medicine principles over the next 5 years (Figure 2). Their top three priorities were:

- building a personalised approach to care (37%);
- reducing harm and waste (23%); and,
- tackling unwarranted variation in practice and outcomes (14%).

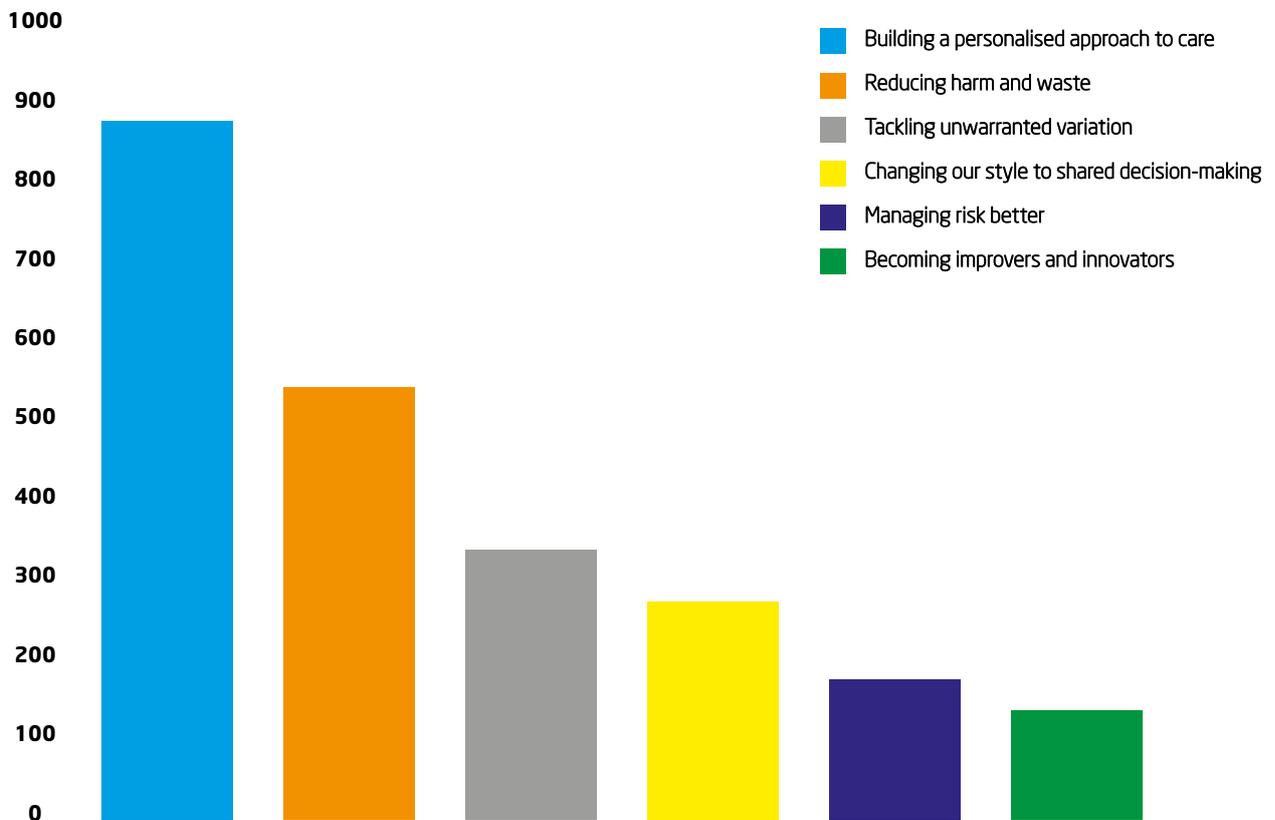
In terms of the future direction of Realistic Medicine, the top three priorities were:

- wider engagement with the general public to improve understanding of Realistic Medicine (28%);
- a focus on how Realistic Medicine can be applied to specific areas of healthcare (26%); and,
- a focus on optimising the wellbeing of the health workforce to enable the delivery of Realistic Medicine (13%).

Nearly 500 respondents provided additional free-text comments which offered a valuable range of insights into how people experienced Realistic Medicine in practice.

The results will be available in full on the Realistic Medicine website.

Figure 2: Top priorities for Realistic Medicine over the next 5 years [base: 2362 respondents selected their top priority]



REFLECTIONS

I am truly delighted to have received almost 2,500 responses to our survey and I am most grateful to all who took time to share their views. It is heartening to see the extent to which staff feel that Realistic Medicine matches their own personal beliefs and values about how healthcare should be practised. It is also reassuring that so many people believe that Realistic Medicine has had a positive impact on the way they practise already. I recognise that it will take time to fully embed Realistic Medicine across our health and care system but we are off to a great start and I remain wholly committed to achieving this.

It is perhaps not surprising that just over half of all respondents were doctors given that much of our engagement on Realistic Medicine has focussed primarily on the medical profession. But I firmly believe that Realistic Medicine principles and values are for all health and care professionals, not just doctors. That's why I am particularly pleased to have received such valuable feedback from all of the nurses, Allied Health Professionals, pharmacists, dentists, managers and finance staff who took part in the survey.

It has been particularly helpful to elicit people's views on the barriers to implementing Realistic Medicine and to understand their priorities for the future. Already, work is underway to address them. The Realistic Medicine Leads in NHS Boards were newly in post at the time of the survey but are now well placed to provide the local leadership on Realistic Medicine that some people felt was lacking. An NHS Education for Scotland Education Lead for Realistic Medicine was also appointed in January 2019 and will support the national development and coordination of training in Realistic Medicine. And the Citizens' Jury has given us valuable insight into the public engagement needed to promote and support shared decision-making.

The survey and Jury findings give us a clear indication of where we must now focus our efforts. They will inform a new national delivery plan which will set out the action we will take over the next three years to further support professionals, and the public, to practise Realistic Medicine.

It is also clear that Realistic Medicine is a vision shared, shaped and delivered by not only those working in health and social care but also the public. I am therefore convinced that it has been worthwhile to use my Annual Report this year to address some of the themes emerging from the survey and the Jury and to focus on our most important priority – 'Building a Personalised Approach to Care'.

Please note: not all respondents answered every question in the survey and so the percentages presented in this section are based on the number of responses to each question [this base number varies slightly between questions].

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