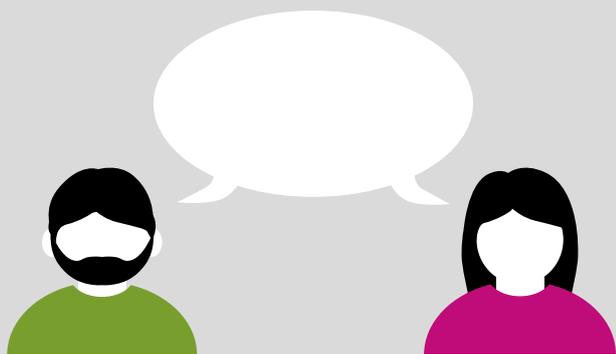
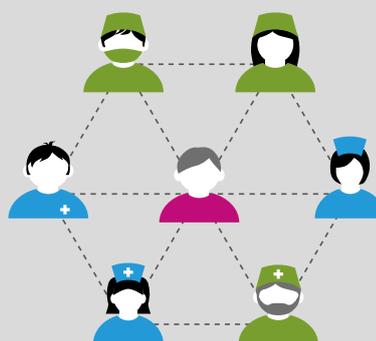


PRACTISING REALISTIC MEDICINE



CHANGE OUR STYLE TO
SHARED DECISION MAKING?

BUILD A **PERSONALISED**
APPROACH TO CARE?



**REDUCE HARM
AND WASTE?**



REDUCE **UNWARRANTED
VARIATION** IN PRACTICE
AND OUTCOMES?

MANAGE RISK BETTER?



**BECOME IMPROVERS
AND INNOVATORS?**

'A note to patients when all else fails'

Sometimes the needle is too blunt.
The stethoscope is too quiet.
The scalpel will not cut.
The scissors chew like old men's gums.

Sometimes the book has not been written.
The pill cannot be swallowed.
The crutches are too short.
The x-rays hide like dirty windows.

Sometimes the thermometer will not rise.
The plaster will not stick.
The stitches cannot hold.
The heart conducts a normal ECG.

Then I have to ask you what to do

Which is what you might
have wanted all along.

Glenn Colquhoun

'A note to patients when all else fails' by Glenn Colquhoun, from Playing God: Poems about Medicine (Steele Roberts, 2002), by permission of the author.

Also available in Tools of the Trade: Poems for new doctors (Scottish Poetry Library, 2016)

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INTRODUCTION FROM THE CHIEF MEDICAL OFFICER

INTRODUCTION



When I wrote to doctors across Scotland in 2016 describing the principles of Realistic Medicine I was not confident that they would read my first annual report let alone agree with the sentiments expressed. Two years later, however, Realistic Medicine has become embedded far beyond the medical profession and in numerous contexts in Scotland, a “social movement” to some extent but also being deliberately written into NHSScotland health and social care policies, guidance documents, teaching and learning packages, information for patients, medical school curricula and the selection process for medical students. It has been welcomed by very many healthcare professionals from multiple disciplines and this extends now across the world with many tens of millions of impressions on Twitter and influence on healthcare policies worldwide. There has been enthusiasm from our partners in the third sector, the General Medical Council (GMC) and British Medical Association (BMA), the Royal Colleges, and of course very importantly the public in Scotland, as you will see in this report – *Practising Realistic Medicine*.

There have been challenges put to me – the most common being lack of time. Lack of time to really discuss people’s priorities, lack of time to ensure they have all the information needed to make a fully informed, shared decision, while aligning with many and varied expectations. I also feel the pressure of time in my antenatal clinic and I recognise these issues and share some of the other frustrations with the “system” which are described to me. Some of those challenges have been countered by fellow professionals – “don’t make a major decision in one appointment”, “offer people the chance to discuss at home and come back”, but this is not always possible or desirable, particularly in the emergency situation. There is recognition too that some of our colleagues are very good at this difficult communication, even when under pressure of time.

There is a need to learn from those who do this well but also to teach communication and recognise levels of health literacy rather than make assumptions about inherent skill or knowledge. This report builds on the principles I have discussed in *Realistic Medicine* and *Realising Realistic Medicine*.

I keep coming back to the tremendous privilege it is to be a doctor. Many have commented to me that Realistic Medicine brings them back to the reasons they wanted to work in health or social care in the first place. A third year medical student spoke to me after one of the first Realistic Medicine talks I gave. “I don’t want to be rude” she said, “but I don’t really see why we need this report – isn’t this what everyone should be doing anyway?!”

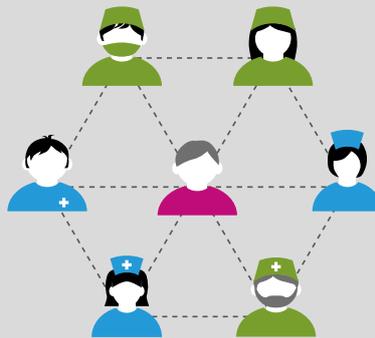
While we rightly set high value on the care we provide for others, at times the “doctor as human too” may be left out of the equation. Sometimes attitudes within and between professions fail to recognise how essential all members of the team are across multiple disciplines and from the most junior to those with most experience. We are our own worst enemies at times. A new chapter in this report examines how important it is to value our staff and we know that this will have a positive effect on the outcomes of our patients. I hope that this latest report will help to translate the principles we have already described into practice in real life, working in whatever part of the system you are delivering care. The most important part of our jobs is to provide the best care possible, but in order for that care to be optimal it is essential that we look after both ourselves and each other.

The intention of this report is to support and accelerate the transition from a discussion about the principles of Realistic Medicine to their practical application in the complex world of health and social care. In the future, I anticipate that the way we communicate with you will change further, using a variety of different media and more frequent and practical releases on particular aspects of Realistic Medicine, including tools and case studies, to assist you in Practising Realistic Medicine. I hope you enjoy this report and, as ever, welcome feedback.

CHAPTER 1

BUILDING OUR PERSONALISED APPROACH TO CARE WITH PEOPLE ACROSS SCOTLAND

BUILD A **PERSONALISED**
APPROACH TO CARE?



HOW DO WE KNOW THAT THE PUBLIC REALLY WANTS "REALISTIC MEDICINE"?

Building a more personalised approach to care, in partnership with people through shared decision making, is perhaps the most important aim of Realistic Medicine, and perhaps one of our greatest challenges.

Evidence-Based Medicine remains at the core of informing best practice and guidance, but for it to truly take place, we must use best available evidence, clinical judgement and patients preferences together. This is especially true within our complex modern healthcare system and when applied to patients with multiple conditions. In chapter 6 this premise will be developed further.

Knowledge requires integration with personal values and preferences. As clinicians we can become very risk averse at a system level, over relying on scientific evidence to inform treatment choices. Through shared decision making we must get better at determining what matters most to patients. *Practising Realistic Medicine* requires care that is coproduced in partnership with the people receiving it – person-centred, holistic care. We need to readdress the balance.

People must be empowered to discuss their treatment fully with their healthcare providers including the possibility that a suggested treatment might come with side effects – or even negative outcomes. Everyone should feel able to ask their doctor why they have suggested a test, treatment or procedure, and all decisions about a person's care should be made together.

But how do we know that patients and the public really want Realistic Medicine? Quite simply, we asked them. Several strands of work have already been commissioned that seek the public's views on Realistic Medicine.

PATIENT SURVEYS

In NHS patient surveys, over one-third of respondents told us that they would like to be more involved in decisions about their care; furthermore, studies have shown that involving people, their families and carers in decisions about their care leads to safer care.¹ They have expressed interest in not only having their care discussed jointly, but being fully involved in the decision making process itself.

CITIZENS' PANEL

In *Realising Realistic Medicine*, we said that we'd consider the results from the Our Voice Citizens' Panel to further understand public opinion on shared decision making, which we view as central to providing the person-centred care that people really value. The second Citizens' Panel Survey results were published in August 2017, and the public agree. The results show that while 92% of people said they would feel comfortable asking their doctor about their treatment and care options, only 67% had actually spoken to their doctor about them.² Similarly, while 91% of people said they would be comfortable asking about the possible risks and benefits of their treatment options, only 64% had done so.³

When asked to expand on their answers, a number of people commented that the attitude of their doctor had an impact on their inclination to ask questions.

"The willingness to ask some of these questions depends on the behaviour/style of the doctor and how busy they are/or are perceived to be"

CITIZENS' JURY

In *Realising Realistic Medicine* we committed to commissioning a "Citizens' Jury", to give members of the public an opportunity to consider Realistic Medicine in greater depth.⁴

We will hold the Jury in the autumn and expect that its conclusions will help us gain further valuable insight into how members of the public, with the benefit of evidence from experts, view and understand the principles of shared decision making and what might be done to foster it. The Jury's recommendations will then be considered as part of our ongoing plans to embed Realistic Medicine across Scotland.

PRACTISING REALISTICALLY

Many clinicians encourage patients to engage in shared decision making and to have a say. Similarly, most patients want to discuss options and share their opinions about treatment with their clinicians, and clearly many seek to be, or want to be, more involved in clinical decisions. Nevertheless, longstanding cultural

norms can make it difficult for patients to speak up, ask questions, actively participate, or challenge clinicians' expertise. Clinicians serve patients best when we frame treatment and care options in terms of the values and goals that patients and their families articulate.

It is also important to remember that doing less or no treatment can be the best option for some people. We know some patients later regret accepting treatment and that some treatments can add to the burden of illness, taking up time and energy, which could be devoted to other activities that offer more meaning to individuals; time spent with loved ones, or on cherished activities. This may partly explain why clinicians choose less healthcare intervention for themselves. 95% of doctors would not agree to have cardiopulmonary resuscitation at the end of their lives, and 88% would choose not to have haemodialysis.⁵ We should aim to provide the kind of realistic care we would want for ourselves and our families.

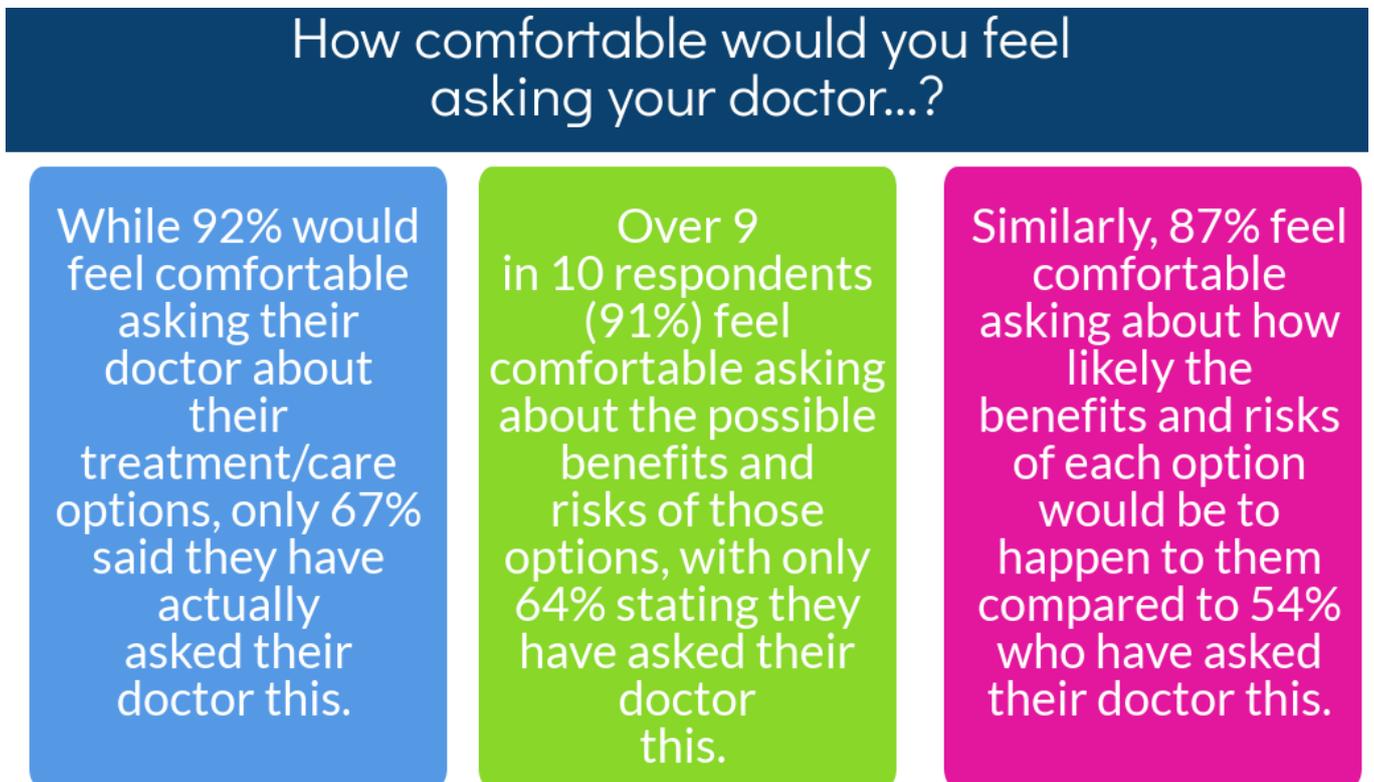
CONCLUSION

As professionals, we must create a more open and trusting atmosphere that facilitates meaningful conversations. It may be that having discussed and weighed up the benefits and risks of the available treatment options, people will choose less treatment, or they may decide not to proceed. They may of course decide to go ahead. The important point here is that people should be guided and supported by us to make an informed choice based on what matters most to them.

Over the next few years we will continue to listen to what the public are telling us to further inform the development of tools and techniques that aim to encourage and promote more meaningful conversations between people and their healthcare professionals. Meanwhile we encourage everyone to consider what they can do to encourage, strengthen and facilitate shared decision making.

The next chapter sets out some of the thinking and work under way that aims to help make shared decision making "the norm" in Scotland.

Figure 1. Infographic of Citizen's Panel Results



Source: Our Voice/Scottish Health Council

CHAPTER 2

CHANGING OUR STYLE TO SHARED DECISION MAKING



By accessing the link and clicking on the various bubbles it will tell you how many positive and negative stories have been received from the public about that theme, and the actual stories will appear. During the period September 2017 to March 2018, a total of 1698 stories were posted on Care Opinion. 68% of these stories were positive and 32% were negative. However, drilling down more deeply, 272 of these stories were tagged with "communication"; "information" or "involved". Of these 272 stories, 61% of these stories were negative and 39% positive. The opposite of the overall picture. Specifically, there were 88 positive stories about communication and 142 negative stories.

Communication is consistently the most negative theme on Care Opinion and within the stories about communication, "information" is the most frequent negative theme.

It may be that as clinicians we think we are engaging in shared decision making more than we truly are and there are lessons for us all on how to do better.

THE IMBALANCE OF INFORMATION

The gradient of power and knowledge imbalance between patients and clinicians needs to be recognised and its implications understood. Often the choices are not straightforward. When people are making decisions about treatment options with a serious condition, they may be frightened and vulnerable; at the time they may seek to be guided by the doctor. It is afterwards that they may question the merits of the treatment decision or experience regret, if their expectations are not met.

HOW CAN WE GIVE PEOPLE THE BEST CHANCE OF PARTICIPATING IN SHARED DECISION MAKING?

Many clinicians will have been faced with "oh you choose, doctor" and sometimes patients may feel they must please their doctor, because they worry their care may suffer. It's vital that professionals do not underestimate the value and skill of working with patients to understand what fits for them and empowering them to make their own choices based on what is most important to them.

GOOD COMMUNICATION

Good communication is at the heart of effective health care, yet it is complex and is based on deeply rooted patterns of behaviour. Effective communication skills lead to improved patient safety, symptom resolution and improvements in functional and psychological status.^{8,9} We know that patients express more satisfaction during consultations where they have been able to express their perspective and objectives – what matters most to them. In doing so they are able to achieve a greater degree of shared decision making.^{10,11,12} Not only are people more likely to have greater confidence in reaching decisions through this person centred approach, but there is evidence that adherence to treatment is improved as well as patients experiencing less regret about treatment choices.

A key part of shared decision making is honesty and realism about possible outcomes; recognising the benefits but also the risks and limitations of treatment in the context of the patients' life and what matters most to them.

Tessa Richards has written in a recent article published by the BMJ about her experience of being treated for cancer:

'The options here are seldom easy, of course, and no one forces patients to embark on chemotherapy, aggressive or otherwise. Indeed, oncologists argue that patient pressure is what makes them prescribe - an apology I don't find wholly convincing. Patients may be desperate for "magic bullets", but they still take doctors' advice seriously. It's a professional responsibility to present people with uncomfortable truths, to be transparent about the limitations of the evidence and how "effectiveness" of cancer treatments is judged, and to be objective about information on risks, harms and benefits.'

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We know that people want to be more involved in decisions about their care, yet they may not know what to ask, or feel that they don't have "permission" to participate in the decision making process. Building and maintaining trust is paramount. Without trust, people may not disclose all relevant information or follow clinical advice. We must move away from the "Doctor knows best" culture and generate supportive environments where people truly feel comfortable asking questions about their care, and can expect to get clear answers.

HEALTH LITERACY

Health Literacy is an issue in Scotland as it is across the world and can be a sometimes overlooked barrier to having meaningful conversations. We want Scotland to be a health literate society which enables all of us to have sufficient confidence, knowledge, understanding and skills to live well, on our own terms, with any health condition we may have. Professor Richard Osborne, the Director of the WHO Collaborative Centre for Health Literacy, gave this definition of health literacy.

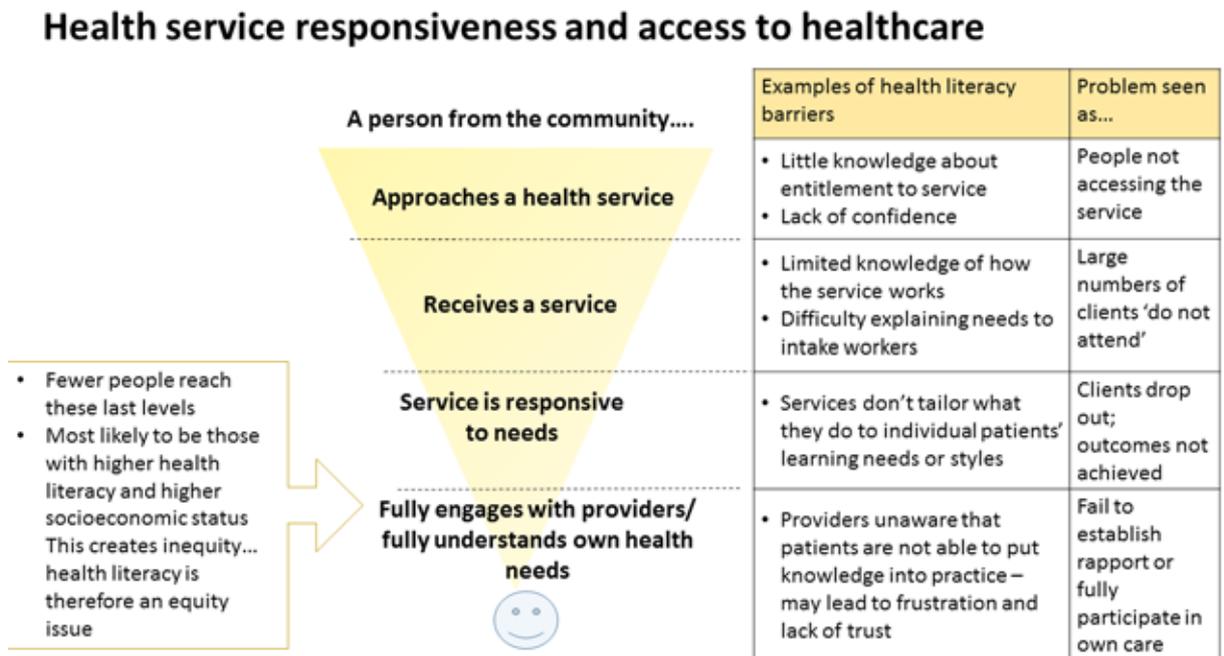
A person's health literacy is their current combination of health knowledge (including general concepts and specific knowledge), beliefs and skills that have developed through life experiences including education, illnesses, interacting with health services and interacting with their families and communities.

Professor Osborne has noted Scotland's mission to make healthcare easier to access as an exemplar for other countries. He has said that while very few countries have a specific health literacy policy, those that do generally seek to raise the health literacy of the population so that they are able to engage in prevention and self-care more effectively. Scotland has this focus too, but avoids a deficit approach, and seeks to make the system fairer, adjusting the complexity and barriers such that all people living in Scotland can have a fair go. He describes this approach as critical, noting the deficit approach to health literacy will continue to promote and deepen health inequalities.

Professor Osborne kindly provided this image (Fig.3) which helps to demonstrate the importance of adapting services to ensure people are able to engage effectively.

Realising Realistic Medicine identified the work on health literacy in Scotland, through the **Making it Easy** action plan, as a key element in creating the conditions for the delivery of Realistic Medicine. It set out our ambition for Scotland to be a health literate society that enables people to have the confidence, knowledge, understanding and skills to maintain good health.

Figure 3. Health literacy: applying current concepts to improve health services and reduce health inequalities.¹³



MAKING IT EASIER

A new action plan **Making it Easier, a health literacy action plan for Scotland for 2017-2025**, was published in November 2017. It focusses on sharing the learning which has occurred so far and embedding this in policy and practice. It also aims to develop more health literacy responsive organisations and communities and design supports and services which are better able to meet people's health literacy needs.



A key element of Health Literacy is the co-production of services between clinicians and patients. Throughout Scotland, forward thinking clinicians and patient groups have already been adopting some of these philosophies and engaging in quality improvement projects which are co-produced by clinicians, patients and carers. One such example is the Helping Us Grow Group (HUGG) in the Neonatal Unit, of the Royal Hospital for Children, Glasgow.

We are also keen to learn from successful approaches which have been developed elsewhere. The Ophelia (**OPTimise HEalth Literacy and Access**) process was developed in Australia. This was trialled by the Health Foundation in the UK among recent immigrants and people with COPD and is being applied in several other countries. The project resulted in a wide range of positive and innovative impacts: citizens were empowered, and at times even thrilled to contribute, and frontline practitioners also felt genuinely respected and efficiently shared their local wisdom.

The new **Health and Social Care Standards** feature in Making it Easier, the Health Literacy Action Plan. The standards promote involvement and shared decision making for everyone who experiences health and social care services. Health and Care Professionals need to reflect on how we can make this a reality.

On the **Health Literacy Place** website, you can find some excellent examples of work, tools and techniques which can be helpful in improving health literacy. We encourage you to consider whether there are projects in the Health Literacy Place that might inspire you to start up your own health literacy project.

ASKING THE RIGHT QUESTIONS MATTERS

Question prompt sheets are effective and inexpensive interventions used in cancer care, enabling patients to become more involved in medical consultations.¹⁴ Increases in question asking have been associated with significant increases in patient satisfaction.¹⁵

In *Realising Realistic Medicine*, we highlighted that some NHS Boards are encouraging people to ask their clinicians 5 questions, to help them make informed choices about their care.

Asking the Right Questions Matters

To help ensure you have all the information you need to make the right decisions about your care, please ask your doctor or nurse:

- Is this test, treatment or procedure really needed?
- What are the potential benefits and risks?
- What are the possible side effects?
- Are there simpler, safer or alternative treatment options?
- What would happen if I did nothing?

Choosing Wisely
UK

REALISTIC
MEDICINE

Healthier
Scotland

NHS Borders, Lanarkshire, Forth Valley, Borders and Dumfries and Galloway are all piloting the 5 questions and we encourage the remaining Boards to follow suit.

Evaluation of the 5 questions approach is under way so that we can understand their impact on patient care and determine how useful they are.

"The questions were great, really explained everything to me the staff were super helpful, they are fine examples of the caring professions."
Patient, NHS Forth Valley

HELPING US GROW GROUP (HUGG), ROYAL HOSPITAL FOR CHILDREN, GLASGOW.

The Helping Us Grow Group (HUGG) is a unique inclusive collaboration of families and staff in the neonatal unit. Our aim is to support parents to be primary caregivers for their baby, no matter how sick, in partnership with clinical staff. This is our model of Family Integrated Care (FIC). Two key elements of our work are education for families and encouraging peer-to-peer support.

Inspired by other leading FIC centres, and motivated by feedback from families in our unit, we organised a programme of innovative daily Family Awareness Sessions (Figure 4). These are held most days from 2-3pm for all families in the neonatal unit and aim to give parents skills and knowledge to care for their baby, as well as an important to meet and support each other. Topics are requested by parents and sessions are led by staff of all backgrounds including staff nurses, nursery nurses, neonatal doctors, pharmacists, dieticians and psychologists. "Veteran" parents, both mothers and fathers, also return to lead sessions and share their experiences.

Figure 4. HUGG Family Awareness Session



Family feedback is extremely positive. Parents tell us they feel more confident, have improved understanding of their baby's condition and care, and are forming strong and long-lasting friendships.

These sessions are organised by a fantastic group of staff nurses, working above and beyond their normal clinical duties. HUGG has empowered them to lead change and improve care for our patients.

In order to foster collaboration we also developed a simple but effective innovation; shared white-boards at each cot-space. Families are able to leave messages for staff, including when they can be present to care, which care they want to be involved in and their baby's likes and dislikes. Staff, especially those on nightshift, write updates and messages of support, including translations for non-english speaking families. Parents are delighted to know that staff are listening. These simple white-boards have created a new relationship with staff, as one parent wrote "thank you for being a voice for my baby".

Another innovation was inspired by a father in the neonatal unit. He told us that he used video messaging for his clients, and asked if we could send him a video of his baby. Working with an industry partner, IT and governance teams we developed and piloted a secure video-messaging system in the neonatal unit in March 2017. Staff create short, friendly video updates for parents when they cannot be with their baby (Figure 5).

Figure 5. HUGG Video Messaging



The positive impact of this innovation has far exceeded all of our expectations. Parents tell us they feel reassured, less anxious and sleep better. They feel a deeper trust and connection to staff who took the time to make and send the video message of their baby. With the support of grateful families we are now spreading our system to over 60 neonatal units throughout the UK, and to other clinical areas in our organisation.

www.vcreate.tv/secure-video-messaging

REALISTIC MEDICINE FLASH CARD

In order to help clinicians and patients have more meaningful conversations about their care options, we've produced Realistic Medicine flash cards. We hope that they will help professionals to further spread awareness of Realistic Medicine and the importance of shared decision making. The 5 Questions will be printed on the flash cards and we very much hope they will support meaningful discussions on ward rounds, in consultations and clinics and as part of clinical supervision. We also hope that you will encourage patients to promote the use of the 5 questions among their families, friends and care providers, as well as aiding you during your clinical encounters.

We plan to distribute the flash cards through our Realistic Medicine Clinical Leads and at events across Scotland.

DECISION AIDS

For clinicians, working in pressurised and busy clinical settings, it may be difficult to know how much people want to know about their treatment options, compounded by limited access to decision aids that are up to date and relevant. While professionals will be used to engaging in discussions about informed consent, going a step further by asking about the person's perspective, health beliefs and preferences is a highly skilled interaction. Talking about risk in the context of treatments is complex and requires careful explanation to avoid misinterpretation.

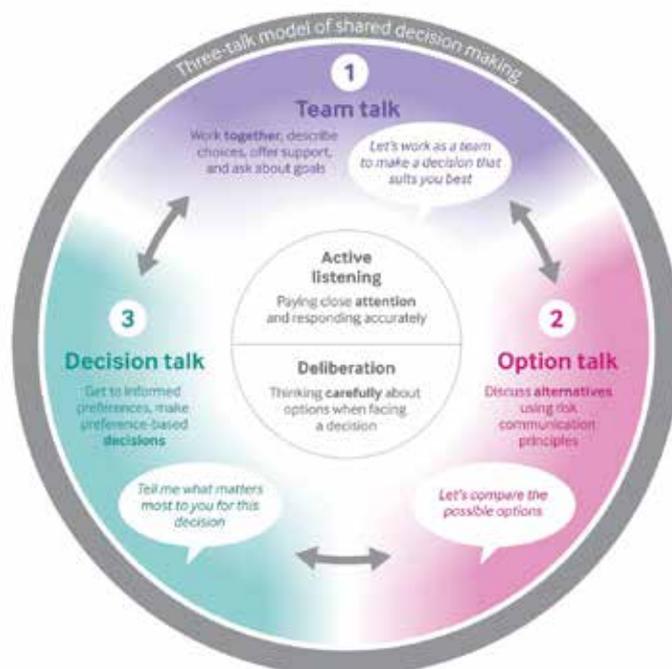
Although shared decision tools are available, these are not often used in routine clinical practice. Decision tools are best used within the consultation as a way of enabling the discussion about choices and options. There are a growing range of up to date decision aids for different conditions, available from the National Institute for Health and Care Excellence (NICE) website, or Right Care (<https://www.england.nhs.uk/rightcare/shared-decision-making/>). There is not a tool for every condition and tools are not a substitute for a meaningful discussion.

CONSULTATION SKILLS TRAINING AND MODELS

Experiential training over just one day is enough to help professionals develop consultation skills that are more patient centred.^{16, 17} As was demonstrated in the MAGIC programme supported by the Health Foundation, "Skills trump tools and attitudes trump skills."

To help embed shared decision making in clinical practice, clinicians can be aided by a model that plans the conversation in stages 1) treatment choices 2) "trade-offs" and 3) decisions, taking into account the persons individual goals and preferences. Glyn Elwyn and others¹⁸ have recently published the "three talk model" which can be used to facilitate shared decision making. The flexibility of this model recognises the different levels of participation and support that people may want to have in the decision making process.

Figure 6. Three Talk Model of shared decision making



MORE WAYS OF SUPPORTING SHARED DECISION MAKING

We must encourage people to take a pro-active approach to making decisions about their care. This could involve providing them with access to shared decision making aids, facilitating audio recordings of their consultations, and encouraging them to view online videos about treatment choices. All of these methods can and do help people make realistic decisions about their care that are right for them and help them recognise the limitations, but also benefits of the options available to them.

SHARED DECISION MAKING AND INCAPACITY

In some instances a person's ability to make decisions about aspects of their care may be impaired. It is essential that all clinicians understand how to assess capacity and use opportunities to maximise a person's ability to make decisions wherever possible. Information on how to assess capacity is available on the **GMC website**.

Sometimes a person will lack the capacity to make a particular decision and clinicians should be aware how to use the legislation which exists to protect the person's rights and provide safeguards. (**Adults with Incapacity (Scotland) Act 2000** and via the **Mental Welfare Commission**).

Shared decision making remains relevant in this group of people and may require enquiry into what a person's views were in the past, discussion with relatives or carers and anyone advocating on their behalf.

CONCLUSION

Shared decision making must become embedded in routine clinical practice. The evidence we have discussed in this chapter suggests that while many professionals practice shared decision making, we can do better. It is the key to strengthening relationships between professionals and individuals, and to reducing unnecessary harm and regret caused by inappropriate or unwanted treatments.

Professionals working in the NHS today are working in challenging environments and making changes to the way we work can be difficult. Nevertheless, we must adapt the way we deliver care to ensure that we are empowering and enabling patients to be in control of their own health and health care. Let's not underestimate the importance of being human; sometimes offering a supportive hand and displaying empathy will give people the courage they need to decide what is best for them.

We hope that some of the methods, tools and case studies highlighted in this chapter will support and encourage your work in partnership with patients to deliver care that people really value.

CHAPTER 3

UNDERSTANDING AND MANAGING MEDICO-LEGAL RISK

MANAGE RISK BETTER?



HOW DOES THE MONTGOMERY DETERMINATION AND LEARNING FROM DISSATISFACTION SUPPORT THE PRACTICE OF REALISTIC MEDICINE?

One perceived barrier to practising Realistic Medicine is the worry that professionals will be criticised for not offering all available treatments and doing all that can possibly be done for each and every patient. Apparent criticism may come from many sources in the form of complaints, external inspection or clinical reviews and litigation. Facing personal criticism can be difficult and distressing, as the overwhelming majority of healthcare workers continually strive to deliver good care and treatment. However, despite best intentions, things can and will go wrong.

Many doctors are understandably wary of missing a diagnosis and this can result in the practice of "defensive" rather than Realistic Medicine. We know that over investigation and treatment can cause harm as well as being wasteful of NHS resources. Realistic Medicine encourages us to recommend investigations and treatments that add value, minimise waste and to personalise our approach to each patient, involving them fully in decision making. Key to practising Realistic Medicine is meaningful communication. In this chapter we will explore the "Montgomery" ruling further, its implications in relation to Realistic Medicine and share information provided by the Scottish Public Services Ombudsman regarding complaints investigated by them.

The medico-legal framework within which we work promotes good communication and shared decision making as being integral to how we should all practise as clinicians. This debate is not new and has been a topic of discussion in Scotland for at least 13 years since the Centre for Change and Innovation published their document "Talking Matters. Developing the Communication Skills of Doctors"¹⁹ – a document that noted "Different patients require different approaches." The complexities of being able to provide a tailored approach to each patient interaction are significant, given the rising demands on healthcare services, changing expectations and variation in processes across different areas.

The lawfulness of patients' consent to medical treatment has been a consistent feature of clinical negligence cases. Before the UK Supreme Court decision in *Montgomery v Lanarkshire Health Board* in 2015²⁰, such lawfulness was effectively judged by reference to what medical experts determined were the appropriate material risks and possible complications to tell patients about. The Montgomery ruling states that healthcare professionals must make patients aware of risk, benefits and alternatives that a reasonable patient would think were material and that a reasonable doctor would be aware are relevant to that particular patient. This emphasises the importance of dialogue and a person-centred approach and a move away from the more paternalistic approach that has predominated before.

The new legal test requires courts to determine what the reasonable person would expect to be told; individual patients now have full autonomy regarding decisions about their health and bodily integrity, bringing the law into line with the modern practice of medicine, including professionally acceptable standards of communication between patients and health care professionals. It is therefore vital that in patient interactions we ascertain what matters most to them, discussing the various treatment options, their risk and their benefits, so they are able to make decisions about their care and treatment.

We asked Professor Emma Cave and Professor Margot Brazier, both internationally acclaimed scholars of medical and healthcare law to consider the implications of the Supreme Court decision for our work in Scotland on the implementation of Realistic Medicine. They jointly commented:

“Montgomery complements the Realistic Medicine focus of the CMO’s previous annual reports and the international “Choosing Wisely” campaign of the Academy of Medical Royal Colleges in a number of ways. It has renewed the focus on the process of consent, and requires that the emphasis of this is patient focused.”

“Accurate and consistent practitioner guidance is essential. The GMC is revising their guidelines and other bodies such as the Royal College of Surgeons have already promulgated guidance. That not all Royal Colleges have done so is in part a result of variations in the relevance of the case - at least insofar as it relates to disclosure - across the specialties. One challenge is to articulate the aspects of the judgment that affect all practitioners and those aspects that are relevant to particular specialties to ensure that healthcare professionals and patients are properly advised. Another is to respond to case law on informed consent that is testing the boundaries of Montgomery”.

Emma Cave/Margot Brazier

Professors Brazier and Cave have suggested that “Accurate and consistent practitioner guidance is essential...”, though as with so many aspects of medical practice, guidance is necessary but not sufficient. Supporting people to make decisions (which is perhaps a more appropriate way to approach the issues raised post-Montgomery than to focus on the challenges of “consenting” people), is complex and involves more than simply eliciting information preferences – there is often a need for sensitive exploration of the values, beliefs or life experiences that have personal significance or meaning.

Perhaps working towards a “request for treatment” from patients, rather than a focus on consent forms would help us to move towards a more person-centred decision making process. Mr Terry O’Kelly, a consultant general surgeon in Aberdeen recently wrote about this for the GMC.

"I am currently caring for two patients who have declined surgery for treatable bowel cancer. In both cases, understanding has been checked using a technique called **teach-back** - asking the patient to recount information in their own words and discussions have been carefully recorded. I have also encouraged patients or a family member to record conversations on mobile devices; and one patient also wrote down their thoughts using a modified version of 'request for treatment' (treatment in this case being 'watchful waiting'). Their decision and subsequent course might not be the one I would choose but I am very respectful of their wishes.

Clearly, these discussions take time and can require more than one consultation to allow for reflection. Assistance from other clinicians, such as specialist nurses, can also be very helpful and providing appropriate information is crucial. Fundamentally though, time must be made available and we have a responsibility to ensure it is. Would we expect any less if we or a family member was the patient?"

Mr Terry O'Kelly, GMC Blog on Consent: empowering my patients to make informed choices

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A task and finish committee is updating the GMC guidance and a key focus of this review will be to develop supporting materials and tools to help embed the principles of the guidance into practice. This is a key element in transforming the relationship between individuals and medical professionals.

We appreciate that there may be barriers to healthcare professionals having more in depth discussions with patients and one that is presented to me frequently is the issue of time. Simply offering the standard treatment or investigation may be quicker, but not necessarily what is in the patients' individual best interests. It is essential that in order to provide high quality, personalised care clinicians are in a position to make the time to have these important discussions. If we are able to move towards engaging in these conversations as a part of routine practice, it is likely this will in some circumstances save time where patients decide against investigations or treatments that they do not feel are right for them. We have heard from teams across Scotland about ways in which they have utilised time differently such as increasing GP appointment times so that issues can be more fully dealt with in one appointment or reallocating tasks which can be performed by other members of the team so that doctors have more time to discuss these

important considerations with patients. We hope that as we launch our Realistic Medicine website we are able to spread learning from teams across Scotland of ways in which time can be utilised differently to enhance the care that we provide every day.

Another common topic of concern amongst clinicians is fear of complaints. Complaints about healthcare are an inescapable component of modern practice. From complaints we can learn and gain insights into how to improve our practice and service.

The Scottish Public Services Ombudsman (SPSO) published a very helpful thematic review of complaints that they have investigated and have provided some guidance and advice to clinical staff on how to use learning from these complaints to make improvements. Communication failures are a common theme in complaints, not just the lack of communication but the nature, frequency and content. Patients and families often don't feel informed, yet those caring for them believe they have communicated effectively.

The Ombudsman review²² found that inadequate consent was the most common recurring issue in complaints they investigated. They have recommended that action should be taken to improve

The **SPSO report** outlined some questions that can be used to begin to understand local systems and processes supporting improvements in the approaches used to support shared decision making and conversations about consent. Some of these are summarised below. We hope that these questions can stimulate discussions as to what might aid better conversations on consent.

- Is there a clear system or tool in place (e.g. a consent checklist) to guide clinicians through the consent process?
- Is there a quality assurance process in place to monitor use and effectiveness of this?
- Is there a system in place to prompt a further conversation with the patient when there is a change in the planned treatment, to discuss the change and seek the patient's decision on whether to proceed?
- Are healthcare professionals prompted to ask about - and record - any specific concerns raised by the patient, together with any advice or options offered in view of the patient's particular priorities (as required post-Montgomery)?
- Is there a quality assurance process in place to ensure that records of consent are sufficiently detailed to meet the Montgomery test?
- Does the consent process encompass a range of options, including the option of no treatment, and discuss the likely outcomes for each (i.e. not just discussing a single treatment)?

We encourage you to consider how these and other questions posed in the SPSO report can help with understanding the ways local systems and processes might be improved to support shared decision making and conversations in relation to consent.

the process for consent including training. The report provides a self-assessment consent check-list for organisations and individuals to use to review their policy and procedures. Critically, it emphasises that organisational culture must support staff to involve people in shared decision making.

As an organisation dealing with health complaints SPSO have a valuable role in enabling us to learn from errors and times when people have perceived care not to have gone well. Given the strong links between the SPSO report and the principles of Realistic Medicine, we asked Rosemary Agnew, the Scottish Public Services Ombudsman for her view on this relationship to Realistic Medicine.



OMBUDSMAN'S COMMENT

In 2016-17 my office handled 1,433 complaints about health. Of these, 495 were the subject of detailed investigations: we upheld in part or full 260 (53%) of them and did not uphold 235 (47%). In the first half of the current year we completed 197 investigations of health complaints: 113 (57%) were upheld in full or part.

Significantly, from 1 April 2017 we changed the way we make recommendations. We now make recommendations in relation to three areas: individual remedy for injustice, learning and improvement, and complaint handling. The approach focusses both on remedying injustice and on learning leading to sustainable improvements.

Monitoring recommendations over time will highlight trends, enable benchmarking and inform how and where the SPSO can give learning and improvement support to public bodies.

Communication with patients is critical to the Realistic Medicine approach. From April to September 2017 the SPSO made 371 recommendations on health complaints and 56 related to failure in communication (across 35 cases). These were not just about lack of communication, but also about the nature, frequency and content. Patients and their families often don't feel informed, yet those caring for them believe they have communicated effectively.

This suggests to me that equipping clinicians with the requisite communication skills is essential. Not only will this enable improved communication; it will enable more meaningful dialogue with patients about their care, and how they give consent. From a complaints perspective, having meaningful conversations, documenting them well and resolving

issues as they arise – in other words taking an open and resolution-based approach – is more likely to make patients feel involved. It doesn't automatically follow that there will be fewer complaints. But it does mean that if they are made we can all be clearer about what happened when and, if there were shortcomings, whether they were system-based, rather than down to individuals.

This is echoed in our "Informed Consent" report in which we highlighted cases where some aspect of the consent process had fallen short.

It is also worth remembering: effective communication is not the sole responsibility of health professionals. Board members, managers and other employees also need to be fully engaged in providing person-centred care and supported decision making with patients. Good communication and informed consent, are integral to the way their organisations deliver care to patients.

Rosemary Agnew

Scottish Public Services Ombudsman

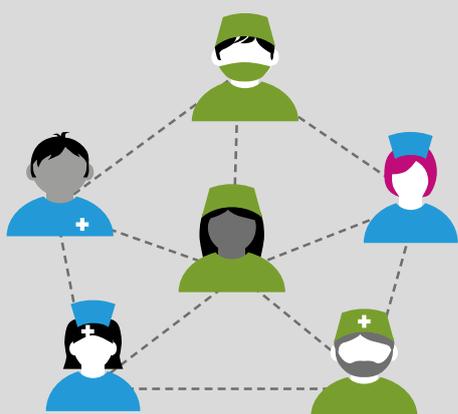
CONCLUSION

Concerns have been expressed about how medico-legal considerations may inhibit practising Realistic Medicine. However, the legal and regulatory standards as they are currently understood and interpreted promote better conversations around treatment, consent and above all shared decision making in their interpretation of good care. This is critical to understanding and being reassured that proportionate personalised care based on what matters most to an individual and is feasible to provide within our NHS is how we should aim to practice now and into the future.

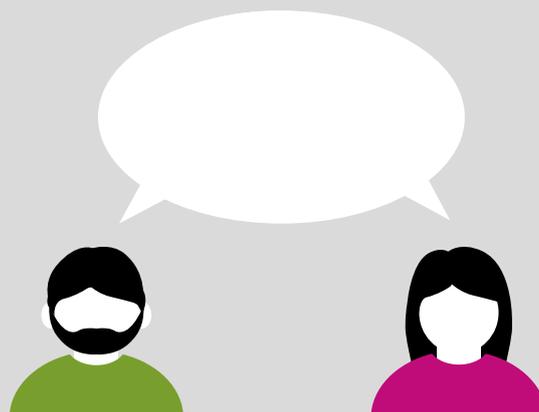
CHAPTER 4

VALUING OUR WORKFORCE

COLLABORATE



CONNECT



HOW DO WE ENSURE THAT THE WORKFORCE IS VALUED SO THAT "REALISTIC MEDICINE" BECOMES THE WAY THAT WE PROVIDE SERVICES IN SCOTLAND?

It is clear that health and social care professionals want to practice with a more person-centred approach as an essential component of fulfilment in their jobs. It is incredibly important that staff feel valued and enabled to lead changes in practice which will help to realise the potential of Realistic Medicine. Our workforce are our most valuable asset and it is vital that they know this and feel empowered to making changes around how we deliver care.

WHAT MATTERS TO OUR STAFF?

"I get a sense of achievement at the end of the day, that I made a difficult experience better for somebody."

Everyone who works in health and social care has their own motivations for doing so. Working within a health or care setting can fulfil some of the most important factors for our sense of purpose and wellbeing. At an individual level, work benefits our physical and mental health and wellbeing.²³ However, to gain these benefits it should be "good work". Good work offers us meaning and personal worth. The best workplaces support us to work autonomously but as part of a team, as well as supporting our development and recognising our achievements. The challenge of providing care is finely balanced; we need professional stimulation to enable us to perform well, otherwise we can become perfunctory and our performance falls. However, if we become overwhelmed with pressure we can become stressed and disengaged.²⁴ Getting this balance right is vital for us to provide Realistic Medicine throughout health and social care in Scotland.

"I have always had a deep personal drive to be the best person I can be. I am very driven to improve the world around me. As doctors, we are immensely privileged to have the trust of our patients, and work with many talented colleagues."

The Francis Report on the Mid Staffordshire Inquiry found that staff morale and engagement were at especially low levels. Staff had become burnt out and disconnected from the core values that took them into healthcare roles in the first place. This

poor engagement and lack of energy for collective responsibility at all levels were significant factors in the acceptance of poor standards of care.²⁵ Organisational leadership placed little value and importance on warning signs highlighted by staff surveys.

It is therefore essential that we listen to our staff, particularly at a time when they continue to maintain high quality care in the midst of increasing complexity, demand, expectation and change. NHSScotland have taken steps to measure and improve staff experience. The iMatter Staff Experience continuous improvement model has been developed in collaboration with staff groups to provide a new mechanism for measuring employee engagement levels across all 22 Health Boards. This has been designed to allow individual teams, managers, directors and boards to measure and understand staff experience and make the necessary improvements based on this shared understanding. Integral to the model is the ability of individuals and teams to shape the action which is taken in response to the feedback.

Engaged staff feel their personal activity is more connected to the purpose of their team and the organisation more broadly. They feel more motivated in their role and able to face the challenges of work with greater flexibility, knowing that they are supported and valued. The correlation between engagement and improved performance is seen not only in healthcare but in many other sectors.^{26, 27} A strong link has been demonstrated between NHS trusts with high engagement levels and better patient and organisational outcomes including lower mortality figures, higher patient satisfaction and lower staff absenteeism.²⁸ Effective care therefore relies on the staff who deliver it. The King's Fund has recognised that staff engagement is reliant on a collaborative approach between leadership and staff. It relies on commitments to common objectives, actively listening to the feedback from staff²⁹ and valuing their input. Allowing staff flexibility and control towards achieving shared goals will contribute to meeting the personal drivers for them too. If this approach is effectively pursued, it will sustain a health and social care workforce to remain connected to their core values and committed to the highest patient care.

However, as highlighted by Francis, this example needs to be set by leaders at all levels of the organisation. When the workforce does not have a sense of safety or trust in their leaders, they are less likely to bring challenges and risks forward. To foster a sense of trust, the workforce need structure, clarity and dependability from leaders to feel that they are truly listening and responding.

There are a number of recent high-profile publications in the UK that remind us how staff perceive their current working experience and the challenges that they face. However, despite these challenges, over 90% of staff feel valued by their patients.³⁰

'If it wasn't for the staff I don't think I would have got there. ALL the staff are fabulous caring and professional, giving a high standard of care. ...if it wasn't for the domestics, nursing auxiliaries, nurses all bands, doctors from juniors to senior that spoke in a way I could understand and come to terms with my condition... I know you all get busy and tired but your staff always show kindness, calmness and caring and nothing was too much trouble... much appreciated'.

Source: CareOpinion

Workforce supply and demand pressures are compounded by the potential impact of both an aging workforce and an aging population on workforce planning.³¹ These issues are recognised, as are the impacts that are felt by people who work in these environments, and we will address these through the implementation of our workforce plans. Scotland is the first nation in the UK to publish a national health and care workforce plan. Part 1 focuses on the acute NHS and was published last June. Part 2 covering workforce planning in social care was published jointly with COSLA in December. Part 3 on primary care staffing is being developed with our partners and will be published this year, following implementation of the new GP contract. A fully integrated health and social care workforce plan will be produced later in 2018, and annually thereafter.

Projections show that we will need to increase staff numbers in future years. From our doctors in training

'The whole experience was very positive and calm with full support provided at every stage. It was clear that all team members were working under a very heavy workload yet everything was done to ensure my daughter and the babies were looked after. Our experience could not have been better'.

Source: CareOpinion

will come the future supply of Consultants and GPs. In the Health and Social Care Delivery Plan, the Scottish Government has committed to increase medical training places by a further 100 over the course of this parliament bringing the total number in 2017 from 898 to 1038. However, an increasing number of foundation trainees are taking career breaks; currently only around 50% of foundation trainees continue directly into higher training.³² Qualitative research from the Scottish Medical Education Consortium has investigated the decision making process for Foundation doctors taking a break from training. Multiple themes were identified, including organisational, occupational, personal life and simply "needing a break".³³

Whilst there remain challenges in recruitment to all available training posts, which affect some specialties such as psychiatry and general practice in particular, there is reassuring evidence that trainees do seem to return to training in the UK within two to three years: 87.5% of the 2014 F2 cohort were in specialty or GP training within three years.³⁴ There is ongoing monitoring of these trends, but we should not be complacent that this trend will continue.

Our understanding of the goals of those who have more recently joined the workforce is that gaining a sense of purpose and fulfilment from work remains a high priority. However, this is in the context of seeking greater flexibility and balance; commitment is balanced with an expectation to be supported and appreciated in return for their contributions, and to be part of a cohesive team.³⁵ In recent years the Scottish Government have implemented a number of measures to encourage a better balance between high quality training and work/life balance in relation to working patterns of doctors in training. Through listening to

the concerns of doctors in training and working in partnership with BMA Scotland and NHS employers the following actions have been implemented to ensure doctors in training achieve a better work/life balance, work on safe and sustainable rota patterns and receive good quality training experience.

- Abolishing doctors in training working seven nights in a row.
- Abolishing doctors in training working for more than seven days or shifts in a row in any working pattern.
- The publication of updated New Deal monitoring guidance to ensure that every doctor in training in Scotland gets to take part in working hours monitoring exercises to report compliance with the New Deal contract.
- We will continue to work with our stakeholders to explore other options including improving rest and catering facilities for doctors in training working out of hours.
- By August 2019 the implementation of a minimum period of rest of 46 hours following any run of Full Shift night working, and joint guidance to create greater flexibility around the allocation of annual leave.

The Scottish Government has also developed a supportive improvement tool to promote safe and healthy working patterns. This initiative, the Professional Compliance Analysis Tool (PCAT), creates an analysis and structured improvement process to address working patterns in terms of three domains:

- Patient Safety
- Trainee Health and Wellbeing
- Quality of Training

It has a clear focus on requiring collaborative working between trainees, training and service leads as a core principle to improve working patterns and achieve intelligent rota design. The PCAT is being applied across all Health Boards in NHSScotland.

The welfare of health and social care staff is critically important with every employer required to have policies in place and to comply with national policies on managing health at work, which includes mental health and wellbeing. For example, Health Boards currently have varying mechanisms in place to monitor stress in the workforce. Support includes, stress audits, staff survey results, monitoring of sickness absence, monitoring use of staff counselling service, attendance at training and skills development. The Scottish Government are working with the NHSScotland Health and Wellbeing group to test interventions focussing on both physical and mental wellbeing to help improve the health and resilience of NHS staff across Scotland. This work will include considering the initial outcomes of iMatter.

Thriving in Medicine

NHS Education for Scotland recognises the need for individual support for staff as well as improvement through organisational change. A pilot course for FY1s delivering skills for 'Thriving in Medicine' is being evaluated. This focusses on personal development in dealing with challenges of a life in medicine. [Supporting web resources have been developed for all staff.](#)

A key aspect to ensuring staff are able to maintain their wellbeing and perform their work effectively is having a safe and supportive working environment. Ensuring that our workplaces are free from a culture of bullying and harassment is integral to this. The Royal College of Surgeons of Edinburgh is running the #LetsRemoveIt campaign to stamp out bullying and harassment which has no place within healthcare or indeed any industry. This is a culture which impacts poorly on patient safety and staff morale and must change in order to ensure an empowered and efficient workforce.

The Royal College of Surgeons of Edinburgh has some excellent resources available on **their website**.³⁶ This includes resources to spread the campaign within local areas and a useful e-learning module. There is information on the legal aspects around these behaviours and information on how to raise concerns. The College recognises that few healthcare staff enter their profession with the intention of becoming a bully but identifies how poorly managed communication,

Figure 7. The Royal College of Surgeons of Edinburgh #LetsRemoveIt Campaign

#LetsRemoveIt



Bullying harms your profession and your patients.

We need a change of attitude towards bullying and undermining behaviour. The Royal College of Surgeons of Edinburgh is leading and supporting a cultural change in practice and performance.

Find out more at rcsed.ac.uk/bullying



particularly in high-pressure situations, can tip into aggressive, intimidating or undermining behaviour. If left unchecked such behaviour can become ingrained within work culture. To combat this, individuals are encouraged to openly reflect on their own practice to ensure they are not adopting poor practices. There is a checklist to self-check personal behaviour, advice on safely acting assertively, on how to give and receive negative feedback and on positive negotiation strategies. What is clear is that combatting bullying and harassment in the workplace is not a matter of getting rid of a few "bad apples". It's about changing our work practices to create a positive, constructive working environment.

There are many changes we can make locally to help change the culture, for example the use of Schwartz Rounds: group meetings for all staff where emotional and social aspects of working in healthcare are discussed. We must consistently demonstrate the attitudes that brought us into a career in health and social care and demonstrate civility, consideration and kindness throughout all roles and levels within our workplace.

"The Happiest Unit in Scotland"

ICU in NHS Grampian have made this the focus of QI projects. The aim is to maintain high team spirit, and improve staff psychological and physical wellbeing. Strands include debrief via Values Based Reflective Practice (VBRP), staff appreciation, highlighting positives at Mortality and Morbidity (M&M) meetings and shared charitable goals.

Effective leadership is vital in order for us to respond to and support our staff and it must be distributed across our health and care systems. A hierarchical, distant approach that does not address these needs will devalue and alienate our staff. Equally, leaders and indeed the complete health and social care workforce should understand the impact of the examples we each set; we reflect the world around us, and should consider how we want that world to look. The challenge within

the workplace is to encourage flexibility and find novel solutions to meet the workforce needs and ensure health and social care remains a desirable career. All organisations that employ, train or represent our staff should find collaborative ways of working towards this goal.

The connection between excellent clinical leadership and high-quality care is now established. Research shows NHS Trusts with the highest levels of workforce engagement have had stable leadership over extended periods, with the same senior leaders continually developing their approach.³⁷ Maintaining a connection between the health and social care workforce, the core values that brought them into work and those of the NHS enables full engagement from staff. However, it is leadership at every level which is needed to bring about this engagement and shared sense of purpose. This leadership in turn will ensure the highest levels of patient safety and care that Realistic Medicine describes. Leadership needs to move from a "command and control" style into more flexible and person-centred collective leadership.³⁸

A Whole-Board Approach

The Medical Education Directorate in NHS Lothian has taken a whole-board approach to supporting trainee wellbeing. Initiatives include near-peer mentoring the 'Lessons Learned in Lothian (LLiL)' programme. This is embedded in the Foundation Teaching Programme, and build on the patient safety and human factors session at induction, 'LLiL' is themed to the patient safety aspect of the FY curriculum and delivered via nine sessions in which FYs learn significant adverse event (SAE) review in a safe, facilitated forum. Future 'LLiL' development will see rollout of this to other training cohorts.

Collective leadership requires responsibility from not just leaders but the entire workforce. A collaborative and consistent approach is needed, with compassion and the aim of continual improvement evident throughout.

High expectations of performance and quality whilst undergoing transformational system change puts leaders at all levels under pressure. To achieve Realistic Medicine, our leadership must focus on promoting a culture for high level care and engagement.

Our collective leadership must have a clear, forward looking vision, shared with the whole workforce. Leaders need to match their actions to their words, and live these values every day. Strong engagement is promoted by team-working, cooperation, learning and innovation.³⁹ Leaders support the workforce to take themselves towards the shared vision instead of imposing a path. The most effective leaders generate a culture of integrity and trust.⁴⁰

"The quality of clinical leadership always underpins the difference between exceptional and adequate clinical services"

Sir Bruce Keogh 2011

There are many examples within health and social care in Scotland where this culture of collective leadership is strong. We need to nurture and grow this culture where it exists, and enable all those coming into the workforce to develop their leadership potential so we can create effective leaders at all levels of care. Project Lift has been created for just this purpose.



Project Lift is a single team and digital platform, created through collaboration between Scottish Government, NHS Education for Scotland, and the Golden Jubilee Foundation.

The Project Lift mission is to establish a system-wide approach to supporting, enhancing and growing leadership at all levels to transform the public sector in Scotland and improve the experience of our people. Project Lift will co-ordinate and oversee 4 key elements of activity:

- Values Based recruitment – getting the right people into senior appointments who live the NHS values.

- Talent Management – tailored support for those with high potential as leaders.
- Leadership Development – multi-professional development and networks.
- Performance Management and Appraisal – giving recognition and value to transformational leadership.

Project Lift looks for all potential leaders, from whatever background, at whatever grade, in whatever role. If you are someone in the NHS who is genuinely willing to develop yourself and those around you, and if you are passionate about improving outcomes for the people of Scotland, Project Lift will commit to helping you live your potential. Please contact the team at www.projectlift.scot/

CONCLUSION

The development of Realistic Medicine began from listening to conversations across the country about what was important to staff in the way that they provided care. As our understanding of this becomes deeper each year, and as we identify the areas for prioritisation, we will continue to engage and to listen about what matters to them, and what gets in the way of being able to practice this way. Some of these will be relatively straightforward to address, some will be more complex and will take longer. Health and Social Care staff in Scotland should rightly be proud of the work they do and the care they provide. It is within our collective power to create the environment to practise Realistic Medicine, supported by an organisational culture with leaders who listen and enable everyone to fulfill their potential.

CHAPTER 5

TACKLING UNWARRANTED VARIATION, HARM AND WASTE



**REDUCE HARM
AND WASTE?**



**REDUCE UNWARRANTED
VARIATION IN PRACTICE
AND OUTCOMES?**

HOW DO WE INTEND TO TACKLE UNWARRANTED VARIATION?

WHAT IS UNWARRANTED VARIATION?

In *Realising Realistic Medicine*, we made it clear that one of the main aims of Realistic Medicine is to tackle unwarranted variation. Variation occurs for a number of reasons. Healthcare systems are complex. Regional differences may arise due to differences in recording information, or due to the needs of the local population. In some cases there may be a range of approaches to treatments, all of which add value, but the best methods have yet to be determined.

However, some variation cannot be explained by the characteristics of the people being treated. Unwarranted variation, a concept developed by Professor John "Jack" Wennberg at Dartmouth, is variation in healthcare that cannot be explained by need, or by explicit patient or population preferences.⁴¹ Recognising unwarranted variation is of vital importance because it allows the identification of:

- Underuse of higher value interventions – i.e. under treatment.
- Over use of interventions which should be used less frequently.
- Over use of interventions which may result in harm.

Data which show variation in interventions do not tell us whether services are good or bad. No one knows the right rate of hip replacements, cataract operations, MRI examinations or antidepressant prescriptions, for example. The right level of an intervention, sometimes called the "warranted level", must be determined by clinicians discussing variation to understand the reasons for it. Only by discussing variation together can we decide whether that variation is warranted or not. Where clinicians agree that the variation is unwarranted, they must seek to find, agree and implement solutions to tackle it.

HOW DO WE INTEND TO TACKLE UNWARRANTED VARIATION?

We know that demand for health and care services is increasing and in order to meet that demand we must consider how to make optimal use of the resources we have to ensure the best possible care for our patients.

Allocative value: allocating resources to different groups equitably, in a way that maximises value for the whole population. This might relate to either a condition or a characteristic e.g. respiratory medicine, which might further be broken down to e.g. asthma, COPD, sleep apnoea etc. Once this has been done, those who manage the service must get together with patients to identify where best value is achieved and how resources are distributed across prevention, diagnosis, treatment, rehabilitation and long term support.

Technical value: improving the quality and safety of services to increase the value derived from resources allocated. This may involve reducing the waste or inefficient processes associated with a particular service or improving safety.⁴²

Personalised value: basing decisions on the best current evidence, careful assessment of an individual's clinical condition and what matters most to the patient. These may include the value they place on good and bad outcomes as even the highest quality healthcare has the potential to do harm.

Realistic Medicine aims to ensure that all treatment offered to patients is able to add value. When we talk about "harm" in healthcare we tend to focus on harm from missed diagnoses or under-intervention. Although this is very important, we must not lose sight of the fact that there may be "hidden harm" involved in over treatment and excessive interventions. Focussing on better value care will therefore involve a change in mind-set for many health and care professionals, including, at times, becoming comfortable with the "gentle art of doing nothing".

VALUE BASED HEALTHCARE WORK PROGRAMME

In order to help ensure that everyone is practising Realistic Medicine by 2025, we need a co-ordinated programme of work that focuses on supporting the delivery of Value Based Healthcare across Scotland. We need strong and committed leadership if we are to fully embed Realistic Medicine principles and values across health and care. Realistic Medicine Leads will be appointed across Scotland in spring 2018. They will be trained in the use of Value Based Healthcare principles and techniques and provide leadership and support to clinical and management teams on Realistic Medicine.

The Leads will develop, co-ordinate and promote a Value Based Healthcare Work Programme for their area, drawing on the tools and support programmes that we will develop nationally. They will engage with their local colleagues to promote Realistic Medicine in practice and will support each other to develop, promote and embed good practice across their region. As a group, they will also oversee improvement projects that will focus on triple value and change the way we deliver care. The Leads will be required to:

- Complete training in Value Based Healthcare principles and techniques.
- Promote Value Based Healthcare and support colleagues with training.
- Engage with local and regional Clinical, Quality and Management teams to deliver Value Based Care and evidence progress against objectives.
- Create the culture and conditions for Realistic Medicine to thrive.
- Champion initiatives that support shared decision making.
- Evaluate local applications for Value Improvement project funding and advise which projects to support.

In *Realising Realistic Medicine*, we committed to commissioning a collaborative training programme on unwarranted variation for clinicians. This programme will be rolled out in spring 2018 and will offer training to our Realistic Medicine Leads and others in the concept of triple value. A modest amount of funding will be available to support value improvement projects and the Realistic Medicine Leads will help to agree the criteria by which staff can apply for funding for projects that will aim to tackle unwarranted variation.

The Realistic Medicine Leads and those who have completed the Value Improvement training will also be trained to use the Atlas of Variation, identifying variation for further local understanding and, where this is found to be unwarranted, to generate and implement solutions that will help to eliminate it.

HOW WILL AN ATLAS OF VARIATION FOR SCOTLAND HELP TACKLE UNWARRANTED VARIATION?

An Atlas of Health Variation shows variation in the health of the population, in health and care, and in health outcomes experienced by people in different geographical regions. The production of a publicly accessible Atlas of Variation for Scotland, supported by an engaged cohort of clinicians trained in understanding variation and influencing change, will be an essential tool in practising Value Based Healthcare.

An Atlas of Health Variation does not suggest an ideal level for procedures, tests or treatment, nor does it suggest that high is bad or average is ideal.

The aim of the Atlas is not to provide answers but to provoke questions and dialogue. These questions will not only lead to a better understanding of the reasons for variation, but will help to identify variation that is unwarranted and potentially harmful. Questions that the Atlas might stimulate include:

- Does the variation matter?
- Are we doing things the same way as in other parts of the country?
- Do we need to change what we are doing?
- Can we learn from successful innovations or best practice guidelines elsewhere?
- Can we share our expertise?

The Atlas will initially focus on helping to identify over treatment and under treatment across Scotland and support clinicians to address this. Month on month we aim to build the Atlas, adding more maps. We will continue engaging with clinicians to identify which indicators to add to the Atlas, ensuring it reflects the needs of the population, is relevant to clinicians and evolves as innovation emerges.

It is expected that the Atlas will, over time, support the development of healthcare provision that is appropriate to the needs of all people across Scotland. We are working with Public Health Intelligence of NHS NSS to ensure that the beginnings of an Atlas are delivered by spring 2018.

CONCLUSION

The desire to identify and tackle unwarranted variation is clear within Scotland and mirrors that which we see internationally. This work has begun across many countries and we can learn from their experience as we introduce this work here. It can only happen if we have useful, accessible data, presented and interpreted in a way that provides insightful knowledge for clinicians, supported with training and education, to discuss locally within a receptive culture. This is the intention of our Value Based Healthcare programme and we look to you for your support to enable it to flourish in order that we provide better health outcomes for our public.

CHAPTER 6

REALISING KNOWLEDGE FOR A REALISTIC ERA



**BECOME IMPROVERS
AND INNOVATORS?**

HOW DO WE BECOME REALISTIC INNOVATORS IN OUR APPROACH TO KNOWLEDGE?

In 1998 Dr Vincent Felitti published The Adverse Childhood Experiences (ACE) Study in the American Journal of Preventive Medicine.⁴³ In it, he examined the relationship of childhood abuse and household dysfunction to many common causes of death in adults, surveying 17,000 middle class Americans to elicit their exposure to eight categories of adverse childhood experience and comparing this against their adult health status, on average fifty years later. The findings were staggering, with a "strong graded relationship" between these experiences and multiple risk factors for health in later life.

As more was understood about the impact of this exposure and the cognitive and physiological effect that it has on children, a compelling rationale for a fresh approach to practice began to form across health, education and criminal justice services. But this rationale challenged both conventional thinking and many of the policies that had been developed to try to help those experiencing addiction; for example, that the root cause of addictions lay within a person's experience rather than solely within the biological structure of the addictive substance. It would take years for this concept to break through and gain wider acceptance.

Chronic stress as a result of adverse experience in childhood changes how children's brains develop and can also alter the development of their hormonal, nervous and immunological systems. These physiological changes increase the likelihood of ill health and multimorbidity by increasing an individual's allostatic load, resulting in premature wear and tear on organs through chronic exposure to a heightened neural and neuro-endocrine response.⁴⁴ However, it is vitally important to understand that this path is not inevitable. More recently, research has demonstrated encouraging evidence that developing resilience, particularly through stable supportive relationships, has a beneficial effect in both reducing this level of health risk and raising educational attainment.

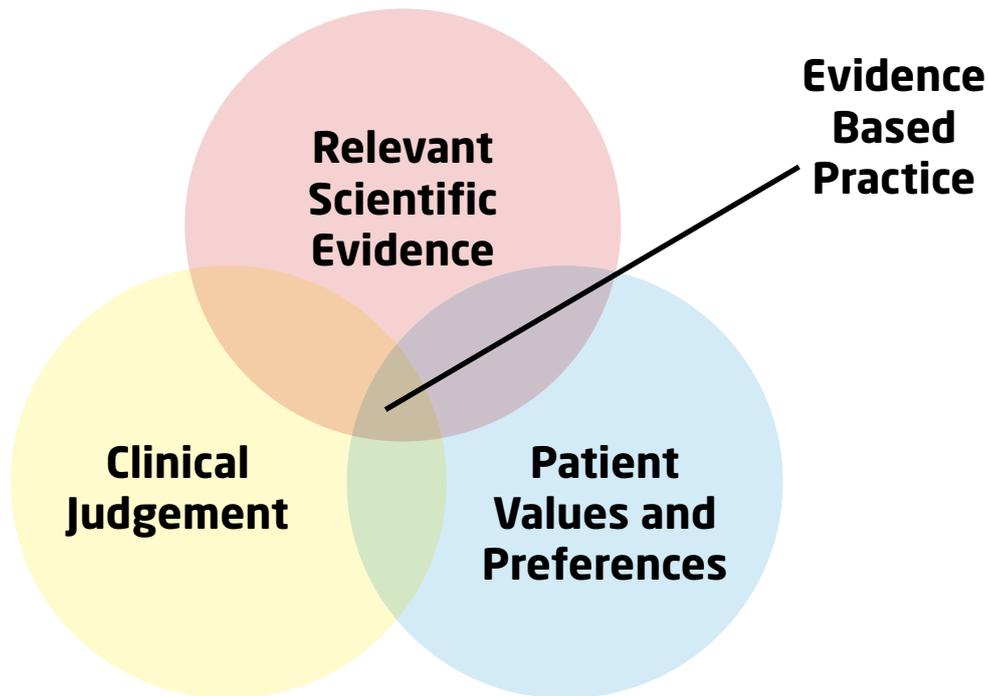
Despite these studies and others that followed, the universal adoption of trauma-informed practice across specialties with interventions aimed at developing resilience in children and young people has been slow. The first Realistic Medicine report spoke about the challenge posed by the knowledge translation gap and

this is a good example of where embedding evidence into common clinical practice takes longer than we would wish to be the case. The Scottish Government's Programme for Government 2017-18⁴⁵ contains a commitment across policy areas to tackle adverse childhood experiences and we welcome this as an indication that this knowledge translation gap is at last being bridged.

But what if we were to take a fresh approach to research and to the evidence that will support Realistic Medicine? Perhaps it is time for us to pause and reflect upon our current approaches if we are to achieve our stated ambition by 2025. Maybe this is an opportunity to try a new way to accelerate the development and presentation of guidance that ultimately will assist in spreading knowledge to professionals and the public alike in a Realistic era. In *Realising Realistic Medicine*, the principles of connection, collaboration, communication and culture were established as key tools for the successful implementation of Realistic Medicine but there is a clear need to develop robust evidence for how best to put these principles into successful practice and to evaluate their impact.

As far back as 1996, Sackett warned us about what evidence based medicine was, and what it wasn't⁴⁶. He cautioned that evidence based medicine should not become "cookbook" medicine. Instead he defined it as the successful integration of the triad of clinically relevant research, individual clinical expertise gained through clinical experience and practice and perhaps most importantly, "the more thoughtful identification and compassionate use of individual patient's predicaments, rights and preferences" in the decisions that relate to their care. In a Realistic approach to evidence based medicine, these predicaments that Sackett refers to might be particularly relevant. We each encounter a variety of socio-economic factors or environmental considerations in those that we encounter that can sometimes make it difficult to extrapolate some clinically relevant research to their experience of the world. Acknowledging this and developing approaches to try to address this lies at the heart of the art of medicine.

Figure 8. Evidence Based Practice (after Sackett et al)



Sackett goes on to say that evidence based medicine should not be confined to randomised trials and meta-analyses, but should involve tracking down the best external evidence with which to answer our increasingly complex clinical questions. This is an approach that is reflected by the changing methodology to recent guidelines produced by the Scottish Intercollegiate Guidelines Network.

Professor John Kinsella is Chair of the Scottish Intercollegiate Guidelines Network (SIGN) that has been developing evidence based guidelines for the NHS in Scotland since 1993. It has an enviable reputation within the Guidelines International Network and continues to evolve its approach to its publications.

Professor Kinsella describes how the use of this evidence is evolving in guidelines. He says, "The traditional randomised control trial has been designed exactly to show that a treatment is better than a placebo, or that one treatment is better than another one. More recently there have been a lot more studies to show that they're equivalent – non-inferiority studies. That's better because you're balancing the advantages of one against the other. The alternative might be easier, less burdensome, faster, fewer side effects or better value."

"We used to have a gradation of recommendation, but that only told you how strong the evidence was. It didn't tell you the clinical importance of it. Now you get strong or weak or conditional recommendations. A strong recommendation simply means that the majority of patients would choose and are likely to benefit from "this". It doesn't mean that everyone should have it. There might be many reasons why a patient might not choose it – co-morbidities, values or preferences to name a few."

Over the last two years, during the conversations that we have had with clinicians across the country, we have often heard concern expressed about "not following a guideline" and the medico-legal implications of this. Professor Kinsella has a view on this. He says, "The whole premise is that it's ok not to follow the guideline provided the reasons for not doing it are well documented. So things that for the majority of people wouldn't be advised for some people it might be the case."

Of course, as well as making these recommendations about what treatments should be used, there is also the opportunity to give advice about those that should not normally be used. Professor Kinsella sees this as a particular strength and says "I've always felt that the

guidelines' real strength is not to reinforce the evidence that many people already knew, because clinicians are generally well informed, but to stop people doing things that are harmful or do not add value to the majority of patients. It's the opportunity to address outlying areas of practice that cannot or do not benefit either the individual or people in general."

He recalls a particular area where this slow adoption of evidence and guidance began to create challenges in his own field of practice, critical care. "Years ago, recommendations had been published that there should be advanced discussion with people with advanced respiratory disease about how they should be managed in the longer term. For a long time before that, we were intubating and ventilating them when they were in crisis, and people struggled with this because the perception was that it was futile, but it felt like we had limited options. Though it's taken time, more people are now managed at home or in assessment units but it takes a long time to filter through." He goes on, "People become more confident to have these difficult conversations but they need to happen in advance. It's not possible to get a balanced view in a time critical situation."

Of course, this also relies on these messages being appropriately and effectively communicated between all those involved in these decisions and who may contribute to care. Crucially, this must include those to which the information relates and must prompt and support an approach responsive to changes in people's conditions, wishes and identified needs.

The Key Information Summary has been part of a succession of tools, including the Electronic Care Summary and Palliative Care Summary, that have attempted to provide this chain of knowledge. Though undoubtedly it has helped, it is time to reflect upon how we can improve this further in the future. A recent workshop sought to develop a shared understanding of the issues here and will help inform planning to produce an enabling digital environment, with data standards that allow people a "form view" of information appropriate for their role and task.

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process is a UK initiative led by the Resuscitation Council UK (RC(UK)). ReSPECT has evolved as a process to support advance and anticipatory care planning (ACP) by prompting realistic shared decision making to guide a person's clinical care in a future emergency where they do not have capacity to make or express choices.

A central aim of ReSPECT is to be truly person-centred and to move away from a binary decision of "Do Not Attempt Cardio-Pulmonary Resuscitation" or "for full escalation" to better reflect people's more complex and evolving situations and values. ReSPECT is a process aimed at prompting and supporting the conversations to establish a shared understanding of what really matters to the individual and to explore which realistic care and treatment choices can support those values in a crisis situation. The form endeavours to communicate that shared understanding in a structured and sharable form in order to ensure the patient's wishes and values are respected at times when they are unable to express them and to enable the staff team to stay loyal to them. It should remain with the patient across all care settings and be immediately recognisable and accessible by all who would benefit from that knowledge to provide the right care for that patient in an emergency situation.

Work on the ReSPECT process and its digitisation, as it matures, will be built on, so that conversations about what matters to people can be recorded and shared in ways which shape the care of people right along the whole pathway of care; from self-management, to palliative and end of life care, via self-directed support and dementia care. Scotland is leading this work with the Professional Records and Standards Body (PRSB), adopting an approach that will see the development of a data standard for recording ReSPECT information in a shareable format. This work will reduce the effort for future application developers in understanding how best to structure and code ReSPECT data and help maximise the re-use and responsive updating of this standardised information between IT systems and to also support other related processes.

One simple step that may assist a more timely translation of evidence into knowledge and practice is to create conditions where academics, NHS staff and policy-makers work more closely together. In a recent editorial in the British Journal of General Practice, Guthrie et al⁴⁷ suggest that there is important "middle ground" research that sits between the tightly controlled studies that lie within the remit of national funding bodies and the service evaluations that too often examine impact only after the roll-out of initiatives.

Professor Stewart Mercer is an advocate for this approach who has published extensively on multimorbidity and compassionate approaches to care. He explains why he feels this methodology is important

to Realistic Medicine, "Middle-ground research offers an attractive approach by providing "realistic research" over a much shorter time span than traditional research, the findings of which would then be more rapidly implemented by NHS partners who were deeply

involved from the outset. The middle-ground approach that we are proposing to inform Scotland's healthcare journey could also lead to and benefit from meaningful collaboration across the UK and internationally."

Figure 9. Strengths and weaknesses in innovation development and evaluation ⁴⁸

	Frontline Clinicians and Managers	Academics
Creating Interventions and new models of care	Normal business for NHS innovators. Strong on feasibility but often does not draw on strongest existing theory and evidence.	Normal business for health services researchers. Strongly based on existing theory and evidence but often inadequate attention paid to feasibility.
Evaluating interventions and new models of care	Often not focused on from the start, and evaluations done tend to use weaker designs that have significant risks of bias.	Emphasise pre-planned, "as strong as possible" evaluation design to minimise bias.
Translating new ideas into practice and ensuring spread and sustainability	The experts in real world implementation but often do not draw on existing theory and evidence.	Often under-estimate the complexity of real-world implementation and many perceive translation to be someone else's responsibility.
Evaluating widespread implementation	Often not focused on from the start, and evaluations done tend to use weaker designs that have significant risk of bias.	Have relevant methodological expertise but not commonly engaged in real-world evaluation, although now partly incentivised by Research Excellence Framework requirements to demonstrate impact.

A good example of this has been the work of the Scottish School of Primary Care and NHS Health Scotland in creating an evidence collaborative to support the transformation of Primary Care in Scotland. This is not just about evaluating impact and implementation of NHS-led innovation, but collaboration to develop complex interventions and new models of care that Professor Mercer says can be "evidence based, theory informed and feasible".

He says, "Achieving the aims of Realistic Medicine will require robust evidence not only on what works, but also for whom does it work, and under what circumstances. This will be needed to know what interventions can be implemented and scaled up, and their likely effectiveness and cost effectiveness."

This is a methodology that will be adopted as we

embark on a research and evaluation programme that will accompany Realistic Medicine. To do this, we intend to embed researchers within the Realistic Medicine policy team to lead this programme along three tracks, examining the clinical, social and economic impact of Realistic Medicine as it progresses and developing further evidence to inform future approaches.

We must ensure that this evidence and guidance is readily available for professionals and public alike, using innovative approaches that maintain the integrity of the therapeutic consultation but with the aim of developing greater confidence in self-management and shared decision making. A Realistic approach to knowledge might combine three sources of information for effective shared decision making:

- Contextual: social factors, environmental support

- Personal: life experience, What Matters
- Clinical: external evidence, clinical experience

Discovery projects are underway as part of the national roadmap to learn how decision support can contribute to the goals of Realistic Medicine. This early focus has been on shared decision making and reducing unwarranted variation and even at this stage their contribution is encouraging.

For example, in 5,692 cases of people living with diabetes and co-morbidities in NHS Tayside and NHS Lothian, and whose clinicians used decision support software embedded in the SCI-Diabetes patient record system, people were:

- 4-9 times more likely as case controls to have essential checks carried out to prevent complications (foot, vision, cardiovascular and kidney disease)
- Significantly more likely to have effective blood glucose control and reduction in acute kidney injury than case controls ($p=0.003$).

The antimicrobial prescribing decision support application, launched in late 2016, now receives 1760 sessions per month whilst shared decision making tools are being tested to support the management of chronic pain, medicines review for people with multiple conditions and implementation of new pathways for gastro-intestinal conditions. These tools will be embedded in primary care clinical systems and also be available as websites and downloadable mobile applications.

“These tools to support shared decision making are exactly what I think we need, locally and nationally, particularly for complex conditions like chronic pain.”

Prof Blair Smith, National Clinical Lead for Chronic Pain

It is critical that this knowledge is accessible for the public too. This, after all, lies at the heart of shared decision making and must be made available in a way that recognises the spectrum of health literacy levels. Indeed, it is fundamental to the House of Care model for chronic disease management that has been highlighted in previous reports and is now being introduced across the country. For example, NHS Lanarkshire libraries are providing training for

health and social care staff in health literacy. They are partnering with public libraries and voluntary organisations so that healthcare staff can signpost patients to relevant sources of information and support.

Library and Information Services across the NHS, local authorities, health and care practitioners and the voluntary sector have a key role to play in achieving a joined-up, coherent approach to making use of many types of knowledge in our interactions with people. More people visit public libraries each year in Scotland than visit cinemas and Premiership football matches combined and as the services that these libraries offer evolve, it is vital that we work together to ensure understandable health information is available within this trusted environment.

Public libraries are building their role as community access points for quality assured health information. NHS library services source evidence to support patient-led decisions and support practitioners to develop their skills in helping service users to use information. The Scottish Library and Information Council is funding a project led by The ALLIANCE in collaboration with public libraries, the Scottish Government eHealth team, and NHS libraries, to deliver a national programme of training in health literacy and self-management for public library staff across Scotland. During Self-Management Week, this collaboration delivered a promotional campaign and the toolkit *Going in the Right Direction*⁴⁹ about using library and information services for self-management and improving health literacy.

CONCLUSION

In his 2003 paper “Disseminating Innovations in Health Care”, Berwick stated that failing to use available science is costly and harmful; it leads to overuse of unhelpful care, underuse of effective care, and errors in execution.⁵⁰ It is ironic that 15 years later we have failed to fully capitalise on the recommendations that he made within that paper on how to accelerate the diffusion of innovations within organisations. Across Scotland, there is much excellent work that will assist us to meet our shared aim of *Practising Realistic Medicine*; ensuring that the evidence and knowledge gained from this becomes embedded in our practice is something that we hope we will all commit to. Across the country, networks of people are coming together to talk, plan and test new ways of working to help us realise Realistic Medicine. As you do this, please

commit to ensuring that others may benefit from the knowledge you develop so that we may all learn and improve together.

Figure 10. Berwick's Seven Rules for Disseminating Innovation in Healthcare

Berwick's Seven Rules for Disseminating Innovation in Healthcare

Find Sound Innovations

Find and Support Innovators

Invest in Early Adopters

Make Early Adopter Activity Observable

Trust and Enable Reinvention

Create Slack for Change

Lead by Example

CHAPTER 7

A REALISTIC APPROACH TO POPULATION HEALTH

Figure 11. Social determinants of health



Source: NHS Health Scotland

CAN WE USE REALISTIC MEDICINE PRINCIPLES TO INFLUENCE THE WIDER DETERMINANTS OF HEALTH?

Health is more than just an absence of illness: it's a resource that enables us to live lives we have reason to value.⁵¹ That will mean something unique to each of us, whether an older person keeping active and mobile so they can continue to visit friends and family, a new mother supported to return to work after post-natal depression, or a child growing up in an environment that allows them to flourish and reach their full potential.

To realise this for the Scottish population, we need to think broadly about the factors which shape our health. These range from the individual, to the local, to the national, to the international, and are sometimes referred to as the wider, or social determinants of health.⁵²

Everyday obstacles to a healthy diet

"I want to feed my family a healthy diet, but rising food costs prevent me from doing so. I can buy 20 sausage rolls for the price of one melon; or five packets of biscuits for the price of a loaf of bread.

The unseen costs of cooking meals are also a barrier I face. I have a prepayment meter. It costs me £4.00 to cook a chicken in the oven, so instead I opt for unhealthy ready meal chicken dinners, which only cost 12p to cook in a microwave."

Extract from 'Poverty in Scotland' (2015), Poverty Truth Commission and Scottish Government⁵³

To truly improve health and reduce inequalities, we therefore need not only to provide high quality healthcare but to address the societal, economic, cultural, commercial, and environmental context in which we live.

The potential rewards of doing so are enormous:

- The recent Scottish Burden of Disease study found that if everyone in Scotland enjoyed the same level of health as the most affluent group, we would be one of the healthiest countries in Europe.⁵⁴
- What's good for health and wellbeing often has many other societal benefits. For instance, increasing active travel through better infrastructure and investment can not only increase rates of physical activity but reduce congestion, noise, and environmental pollution.⁵⁵
- In the context of growing demands and costs, acting on these wider determinants is essential to the sustainability of our healthcare system in the decades to come. A recent review found that on average, every £1 invested in public health interventions provides £14 of return.⁵⁶

Just like good healthcare, good population health therefore requires a whole system approach. As health and care professionals, we have a crucial role to play in each part of that system – and in Scotland we have unrivalled opportunities to do so.

We can build on a strong tradition of pioneering public health initiatives to seize new opportunities created by health and social care integration and by legislation on community empowerment. We have a dedicated workforce of frontline health and care staff, many of whom have expertise in quality improvement, and world class health data which is increasingly being integrated with data from other areas of society. Finally, we're a perfect size for innovation.⁵⁷

Following a review of public health in 2015, the Scottish Government has committed to specific actions to improve the health of the nation: to improve local public health partnerships, including reforming how the NHS and local government collaborate on improving health; establishing a national public health body to strengthen the leadership and voice for public health in Scotland; and setting out clear priorities for action across the whole system, recognising the roles that multiple partners must play. The core theme running through the whole reform is that we must work collaboratively to achieve change. The major levers for health improvement in Scotland lie outside the health service, and they are best tackled in partnership with others. This section therefore asks how, as health professionals, we can apply the principles of Realistic Medicine to ensure everyone in Scotland has an equal chance of a long and healthy life and how we might work in partnership with others to best reduce the burden of avoidable ill health that we see daily in our services.

HOW CAN WE REDUCE HARM AND WASTE BY EMBEDDING PREVENTION IN OUR CLINICAL CULTURE IN A WAY THAT IS RESPONSIVE TO THE SOCIAL DETERMINANTS OF HEALTH?

Too often, clinical staff feel they are seeing the same problems again and again at a late stage, when a greater impact could have been made by earlier management or prevention. Many complex healthcare interventions represent wasted opportunities for prevention – at an enormous human and financial cost.

Better and more timely prevention not only improves the lives of individuals but also relieves pressure on the system and makes the work of our clinical staff more rewarding.

Although there are inspiring examples of preventative work happening across NHSScotland, these initiatives too need to be scaled up to the stage where they become embedded in practice, as was proposed in our chapter on innovation and knowledge.

Prevention also needs to address the wider determinants that influence individual behaviour. Focusing on individual behaviours can only go so far towards improving population health, and can even widen health inequalities – because those who already have the most resources are those most able to take up offers of support.⁵⁸

These wider determinants are often much higher priorities for people than achieving better diabetic control or giving up smoking. As we increasingly ask people “what matters to you?”, we need to consider how to respond when they name poor-quality housing, loneliness, or financial worries. Realising our aspiration to person-centred care – and to effective prevention – therefore requires action to understand and address these wider determinants.

One way of doing this is through holistic support in healthcare settings, in the form of advice workers or referral to local sources of community support (sometimes called social prescribing). This doesn't mean that NHS staff need to be experts in these issues. On the contrary, such initiatives can free up healthcare professionals to focus on what they do best – providing high-quality clinical care – whilst at the same time addressing patients' priorities and the wider influences on their health. Here, we can learn much from our colleagues in social care who are very familiar with these approaches.

By making sure that patients are able to address their basic needs and social circumstances, we can maximise the chances that our clinical interventions succeed. For example, stable housing has been shown to improve medication concordance among people with several long-term conditions (including schizophrenia and HIV).^{59,60}

Embedding holistic support into healthcare settings

A number of pioneering schemes across Scotland have recently shown the potential of providing holistic support services in healthcare settings to help people address wider life circumstances affecting their health. These schemes, developed in partnership between the NHS, local authorities, and the third sector, aim to tackle health inequalities and reduce pressure on general practice.

For instance, welfare rights advisors embedded in clinical settings can provide advice and support on benefits, debt, housing, pension and employment issues. A recent pilot project in two GP practices in Parkhead, Glasgow, delivered £850,000 worth of unclaimed benefit entitlement to 165 people and helped identify and manage £156,000 worth of debt.

Given the evidence showing that our income and financial situation is one of the strongest determinants of health, projects like this have enormous potential to benefit patients. They have also been welcomed by GPs, allowing them to focus on providing clinical care.

GP - “It is contributing to reduced time spent by GPs on paperwork relating to benefits, (it) lets us get on with the job we are trained to do.”

Patient - “Before - I was not really managing - I was upset/not doing really well... Now - I can put money towards things.”

Only by realigning our efforts so that we give equal priority to causes as to conditions can we realise the vision of a National Health Service, rather than a National Illness Service. This is a profound shift, but a necessary one if our health system is to truly meet the needs of the public and the demands of the future.

HOW CAN WE TACKLE UNWARRANTED VARIATION BY USING OUR ROLES AS LEADERS AND PATIENT ADVOCATES TO SUPPORT ACTION ON HEALTH INEQUALITIES IN SCOTLAND?

On average, a boy born in one of the 10% most deprived areas of Scotland can expect to enjoy only 44 years of good health – a full 26 years less than his peer born in one of the 10% most affluent areas of Scotland.⁶²

Such profound injustice in life chances based only on the circumstances into which one is born, is perhaps the most powerful example of unwarranted variation in Scotland today.



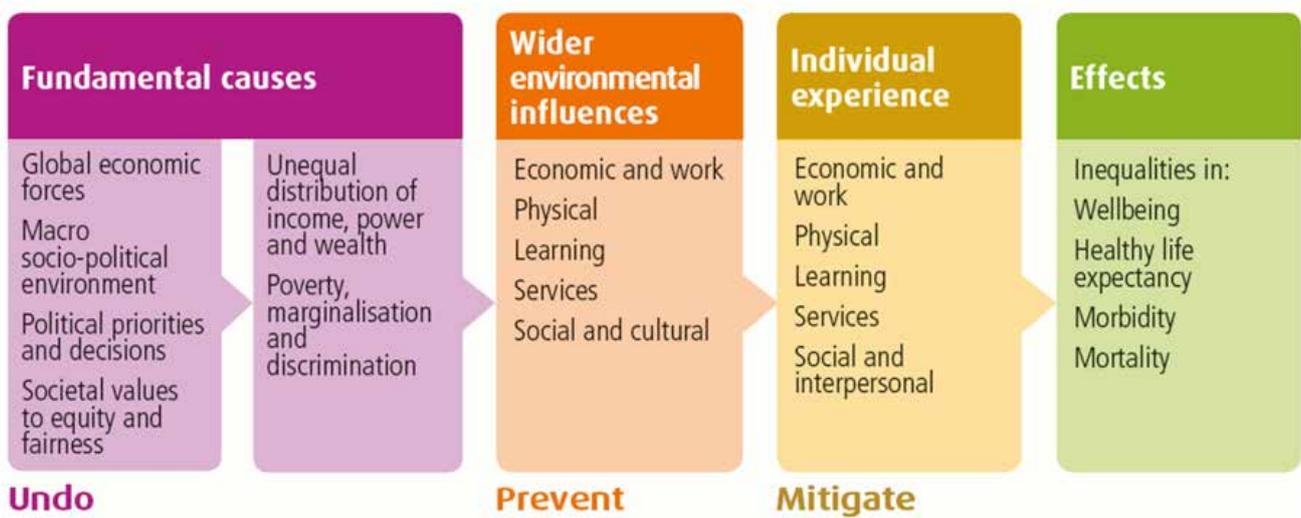
Inequalities across socioeconomic groups in healthy life expectancy, overall life expectancy, and a range of other health outcomes have been static or increasing in recent years. Especially stark inequalities in health are also seen among groups of people with specific vulnerabilities, such as learning difficulties, long-term mental health conditions, refugee or asylum seeker status, or experience of homelessness.

There is now good evidence to show that the “fundamental causes” of health inequalities are the unequal distribution of income, wealth, and power across the population, which in turn affect people’s individual experience of social determinants of health (Figure 12).

The most effective interventions for improving health and reducing inequalities are therefore those which address the fundamental causes and the societal context in which we live – like the introduction of a living wage, pricing of unhealthy commodities and speed limits in residential areas.⁶³ Minimum unit pricing for alcohol, due to be introduced in Scotland on 1st May 2018, is one such intervention.

As health and care professionals, we can tell stories which bear witness to the consequences of health inequalities in everyday practice, and we can amplify the voices of those with lived experience. When we use our expertise, values, and influence to raise awareness of the social determinants of health and health inequalities, and support evidence-based interventions to address them, we maximise our impact on the health of the people we serve.

Figure 12. What causes inequalities in health? NHS Health Scotland’s Model⁶⁴



Changing the culture by changing the context

Scotland has some of the highest rates of alcohol-related harm in Europe, and problem drinking is estimated to cost Scotland £3.6 billion per year. Although alcohol is seen by many as an integral, and unchangeable, part of Scottish culture, our consumption habits are in fact greatly dependent on societal and commercial factors like availability and price. Since 1980, alcohol affordability has increased by approximately 60% - as has the rate of alcohol-related deaths. People living in more deprived communities are more likely to experience adverse health and social impacts of alcohol than their more affluent peers.

The most effective interventions for reducing alcohol-related harm to individuals and communities are therefore those which aim to change the context in which drinking takes place. Minimum unit pricing (MUP) for alcohol, recently deemed legal by the UK Supreme Court after a five-year legal battle, is one example. The introduction of MUP exemplifies what can be achieved through the combination of clinical and third sector advocacy, rigorous public health research, and policy leadership.

The impact of MUP on health and health inequalities will be closely monitored over the coming years through a portfolio of studies covering compliance, availability, consumption, health outcomes, public attitudes, and economic impacts.

HOW CAN WE IMPROVE AND INNOVATE FOR HEALTH BY COLLABORATING ACROSS THE NHS, SOCIAL CARE AND WIDER SOCIETY?

Just as addressing multi-morbidity requires new ways of working across clinical specialties, improving population health and reducing inequalities requires new ways of working across society. The case study below on adverse childhood experiences is just one example, demonstrating how complex problems need holistic, multi-agency responses.

Addressing childhood adversity to improve lifelong health

There is increasing awareness that stressful events occurring in childhood, such as neglect, abuse, or having parents affected by domestic violence or alcohol and drug problems, are associated with lifelong impacts on health and wellbeing.

For instance, a Welsh study found that suffering four or more such 'adverse childhood experiences' (ACEs) increases the chances of high-risk drinking in adulthood by four times, being a smoker by six times and being involved in violence by around 14 times. ACEs are also associated with poorer educational and employment outcomes.

ACEs occur across the population but are more common among children living in areas of higher deprivation. Indeed, poverty itself should be considered a form of childhood adversity given its close association with poorer long-term health, wellbeing, and life opportunities.

To prevent ACEs, we must improve the societal context in which families live through measures to reduce poverty, inequality, and social isolation; parenting support programmes; and multi-agency working that meets the needs of families in a flexible and holistic way. To mitigate the effect of ACEs, we must build resilience among children, families, and wider communities through fulfilling, supportive relationships, and provide public services in a 'psychologically informed' way that recognises and responds to previous trauma.

Addressing childhood adversity therefore requires collaborative action across the whole of society: uniting health, social care, education, policing and justice, housing, and many other areas. A cross-sectoral ACEs Hub has been established to lead this work in Scotland.

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One approach which offers a systematic approach to this kind of collaborative working is "Health in All Policies" ("Partnership working for healthy public policy").

Partnership working to inform healthy public policy

Policymaking in areas outwith healthcare – such as planning, housing, transport, education, and economic policy – has an enormous influence on our health. The most realistic approach to improving health, reducing inequalities, and reducing future demand for care is therefore to ensure that decisions in all policy areas are designed to support good health: an approach known as 'Health in All Policies'.

The Scottish Health and Inequalities Impact Assessment Network (SHIAN) recently brought together public health, local authority housing departments, policymakers, and the third sector to assess the potential health impacts of the Scottish Government's commitment to building 50,000 new affordable homes.

The project identified various potential health benefits including improved mental and physical health due to better housing conditions; increased independence and reduction in falls due to increase in specialist housing provision; and the potential for positive effects on people's financial situation. Features of the places where new houses are built are also important for health – for example greenspace, community amenities and good walking and cycling access.

SHIAN is now working with partners in national policy, community planning, and place-making to ensure that the implementation of the policy maximise these benefits and minimise potential risks.

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Community initiatives have the potential to reach and engage people in ways that the health service cannot, helping individuals and communities to flourish and realise their potential. One example is Sistema Scotland's Big Noise community orchestra projects.

Figure 13. Big Noise Community Orchestra



Improving health, wellbeing, and life chances by making a 'Big Noise'

The Big Noise project, run by Sistema Scotland, aims to transform the lives of children living in disadvantaged communities of Scotland through free musical learning and performance, from six months old to school-leaving age. The programme is being delivered to over 2,000 children and young people within four areas in Scotland: Raploch (Stirling); Govanhill (Glasgow); Torry (Aberdeen); and Douglas (Dundee). Significant attention is paid to ensuring that all eligible children are able to participate, whatever their circumstances, needs or abilities.

An evaluation by the Glasgow Centre for Population Health has shown that Big Noise has positive impacts on children's wellbeing, learning and education, social and life skills, and health-related behaviours.

In particular, Big Noise provides a degree of security, routine and structure to children's time, over and above that offered by school and home life. This is particularly beneficial for vulnerable children with less well-structured home lives.

The next part of the evaluation will focus on children's educational attainment - an important area given its influence on long-term health outcomes.

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Any collaborative endeavour for health must ensure that the voice of the public is at the very centre of decision making. By prioritising the voices of the public and empowering those seldom heard, we can create a health service - and a public health service - that is humane, genuinely responsive, and much more likely to succeed. Greater control by individuals and communities over their own lives is itself also likely to benefit health.⁷⁰

CONCLUSION

To ensure that everyone in Scotland has an equal chance of a life they have reason to value, we must think broadly about the factors that determine our health. As health professionals, we have a role to play at every stage of the causal chain that links "upstream" societal, economic, cultural, commercial, and environmental determinants with their "downstream" impacts on health. We can build on our strong foundation of a high-quality, universal healthcare system to:

- Embed prevention in our clinical culture;
- Ensure our practice is responsive to the social determinants of health;
- Advocate for effective population-level action on health and health inequalities;
- Create collaborations across health care, social care, and wider society; and,
- Empower people and communities to take their rightful place at the centre of decision making.

SECTION 2

A SUMMARY OF THE HEALTH OF THE NATION

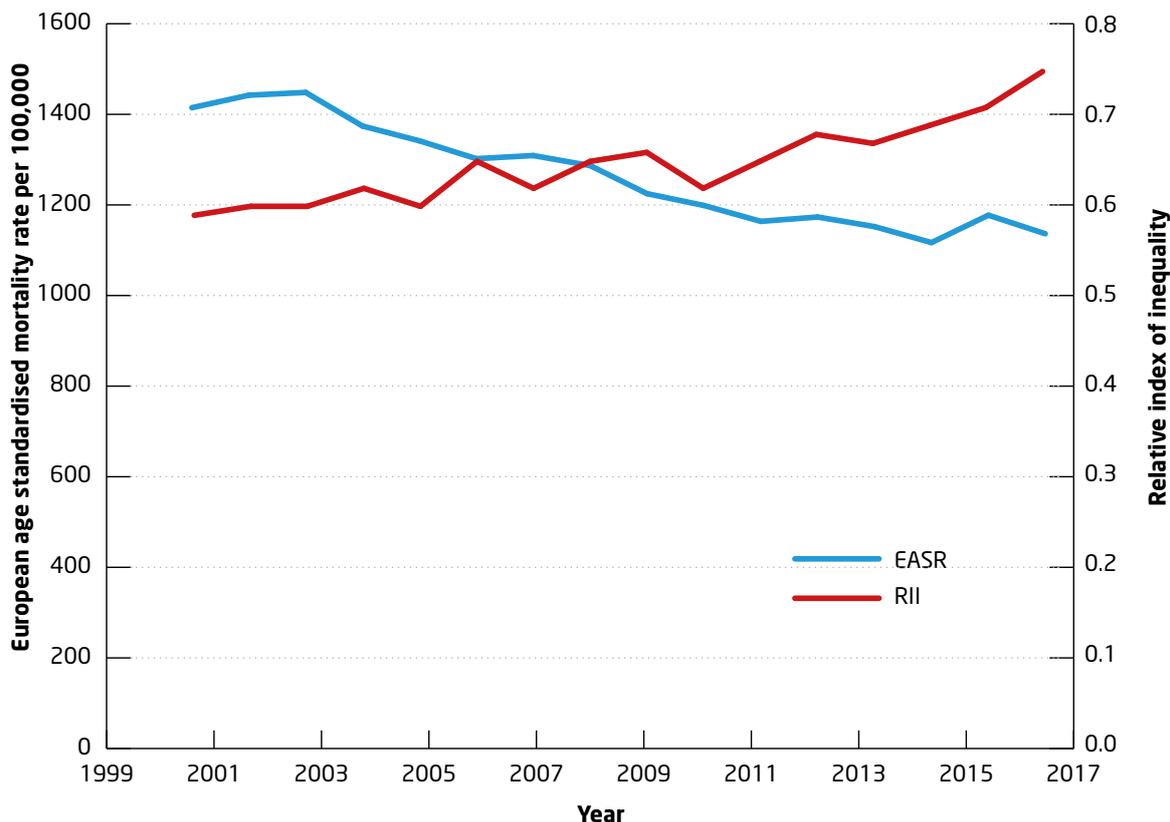


This section will provide an overview of some of the key trends in Scotland's health in recent years. It includes new data from the recent Scottish Burden of Disease Study and the Scottish Primary Care

Information Resource (SPIRE). It also highlights some of the ongoing priorities for Scotland, emerging challenges, public health success stories and frontiers for further development.

TRENDS IN MORTALITY

Figure 14. Between 2001 and 2016, the overall death rate (labelled EASR) continued to decline - but this decline showed a plateau in recent years. Inequalities in death rates between socioeconomic groups (shown by the RII measure) increased over this period.

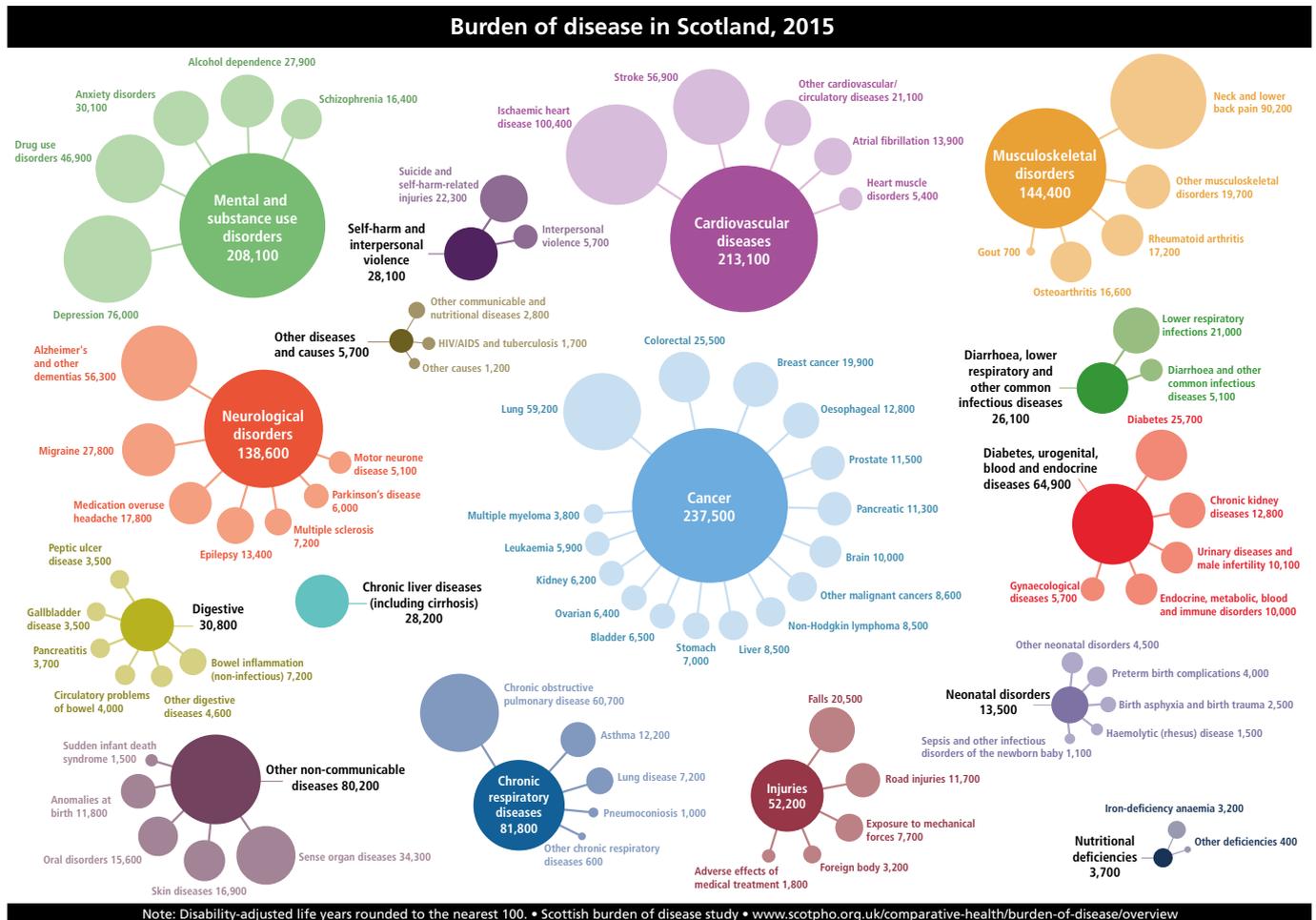


Source: National Records for Scotland

- There has been a long-term decline in death rates in Scotland, a decline which is most obvious when analyses take account of the rising average age of the population, as shown by the EASR measure in Figure 14.
- This decline in mortality has not in general been as rapid as the rest of the UK or other European countries.
- In addition, there was a marked slowing in this mortality decline from about 2011, and an upturn in mortality rates in 2015.
- Mortality rates fell again in 2016, but it is not clear that they have returned to the previous downwards trend.
- There is some evidence that the greatest slowing of mortality decline occurred among people living in the most deprived areas of Scotland. As shown in Figure 14, the relative index of inequality (RII - a measure which summarises how “steep” the inequality gradient is across the socioeconomic spectrum) for mortality has increased between 1997 and 2016.
- A similar slowing in mortality decline has been seen in the rest of the UK and in many industrialised economies.⁷¹
- The reasons for this slowing in mortality decline are not completely clear. It is likely that influenza contributed at least partly to the rise observed in 2015, however the impact of austerity⁷² and pressures on the health service^{73, 74} have also been suggested as possible explanations.

BURDEN OF DISEASE

Figure 15. This infographic from the Scottish Burden of Disease study illustrates what conditions we are living with, and dying from, in Scotland. The size of each "bubble" is proportionate to the rate of death and disability caused by that condition. You can view the image in more detail at: <http://www.scotpho.org.uk/media/1450/sbod2015-bubbles.pdf>

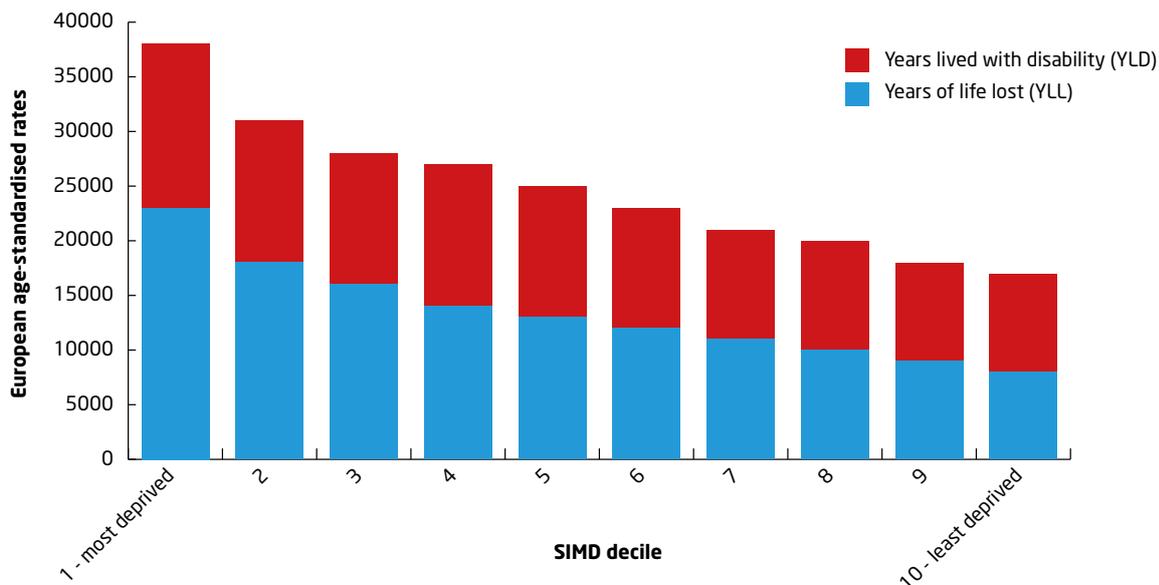


- Efforts to understand the contributors to ill health are often based on mortality figures, but this neglects non-fatal conditions that may cause a substantial amount of suffering and disability.
- The Scottish Burden of Disease project has produced new estimates for the overall burden of disease in Scotland that combine figures on deaths with estimates of the numbers of people living with illness.⁷⁵ These estimates for the first time start to provide a clearer picture of the conditions that cause ill-health and mortality in Scotland.
- These estimates can be used to guide policy and set priorities and are also invaluable for starting to understand the most cost-effective approaches to improving health.

- Figure 15 shows estimates of the total burden of disease in Scotland (combining both death and disability) from the Scottish Burden of Disease (SBOD) project. The large ovals show how this total burden is divided between major groups of disease. The smaller ovals show some of the individual conditions that make up the larger groupings. The figures are disability adjusted life years, which are explained in detail in **the SBOD report**.
- One important lesson from the project has been the variation in the quality of data between different disease areas; for example our data on cancer are much better than our data on musculoskeletal disease. This means that while all of these estimates are based on the best quality data available, some are more reliable than others. Work on enhancing the completeness and quality of data for future estimates is ongoing.

■ Data such as that captured in Figure 15, alongside further data that will eventually become available in the Atlas of Variation, may in time inform different approaches about the way we prioritise the allocation of resources for maximum population health gain.

Figure 16. Rates of ill-health and premature mortality in Scotland show a clear “gradient” by socioeconomic circumstances, with greater socioeconomic deprivation associated with a greater burden of disease.

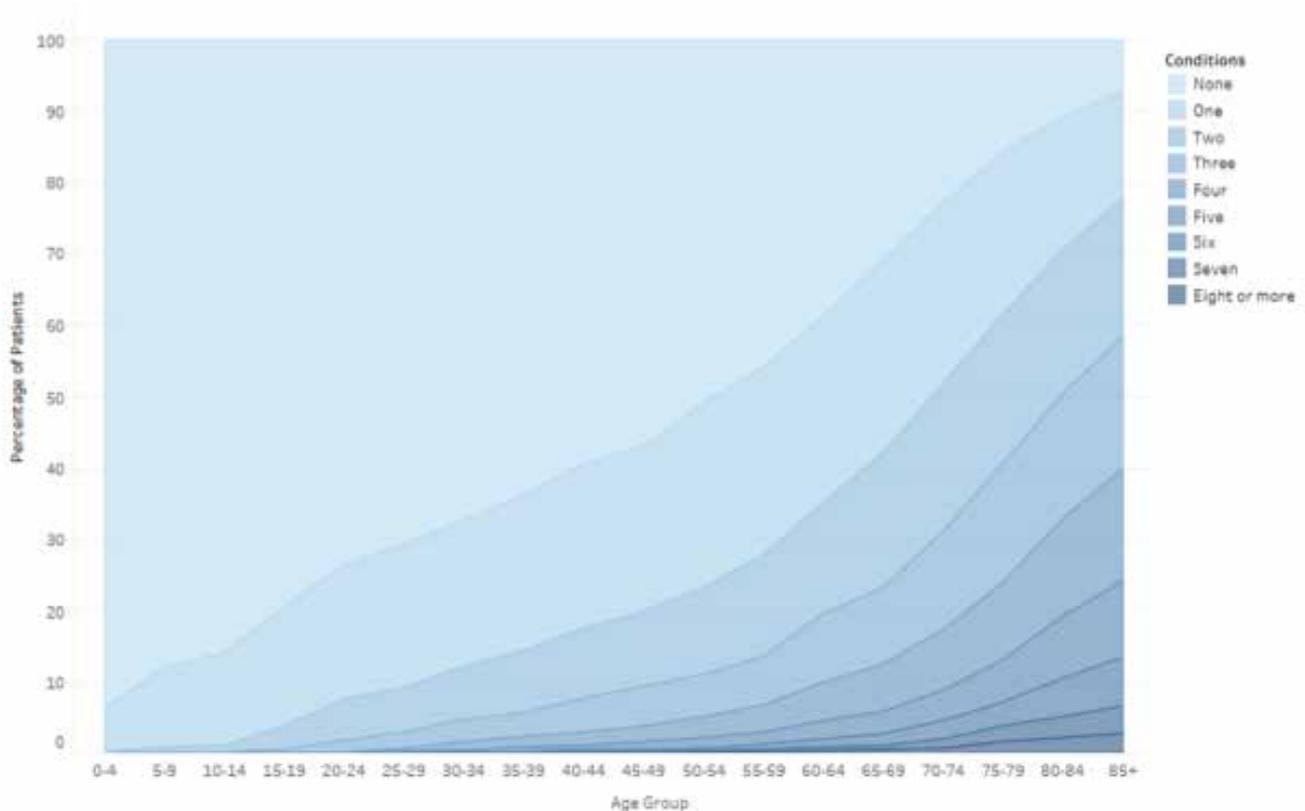


Source: Scottish Burden of Disease Study, 2015. SIMD 1 represents people living in the 10% most deprived areas in Scotland, whilst SIMD 10 represents people living in the 10% least deprived areas. Rates of both YLD and YLL are standardised for age using the European Standard Population, to account for differences in age structure between SIMD deciles. Results have been rounded to the closest thousand and may not exactly match other published figures.

■ The results from the Scottish Burden of Disease study also show how the total burden of disease varies between people living in more deprived compared to less deprived areas of Scotland. The figure shows a steep socioeconomic gradient, both for years of life lost (mortality) and for years lived with disability.

MULTI-MORBIDITY

Figure 17. These new data from the Scottish Primary Care Information Resource (SPIRE) primary care project in Scotland illustrate that the prevalence of multi-morbidity (having more than one long-term health condition) increases with age. Among people 70 years and older, the majority are living with multiple long term conditions.



Source: Scottish Primary Care Information Resource

- These data are from a GP cluster (typically a group of 4-8 practices) in Dumfries and Galloway, collated through SPIRE - a new national resource to enable sharing of de-personalised primary care data, which is currently being rolled out across Scotland (www.spire.scot). SPIRE allows us to look at multi-morbidity in this way by GP practice for the first time in Scotland.
- Figure 17 shows the proportion of people with multiple long-term conditions by age group: as you get older, the number of long term conditions ("multimorbidity") you have tends to increase. However, this is not something that only affects older people: most people with multi-morbidity are under 65 years of age.
- Previous research has shown that multi-morbidity is associated with increased primary care consultation rates and polypharmacy, increased rates of unplanned hospital admission, and with lower quality of life.⁷⁶
- The onset of multi-morbidity occurs on average 10-15 years earlier in people living in the most deprived areas of Scotland compared to the most affluent. People living in more deprived areas are also more likely to experience both physical and mental health conditions.⁷⁷
- Information like this from SPIRE helps GPs and those in the wider primary care team improve quality of care for those with multiple long term conditions by, for example, reviewing the number of drugs they are on and targeting relevant support. It also helps in the planning of both primary and secondary healthcare services, informing decisions about workforce planning, resource allocation, and standard setting.

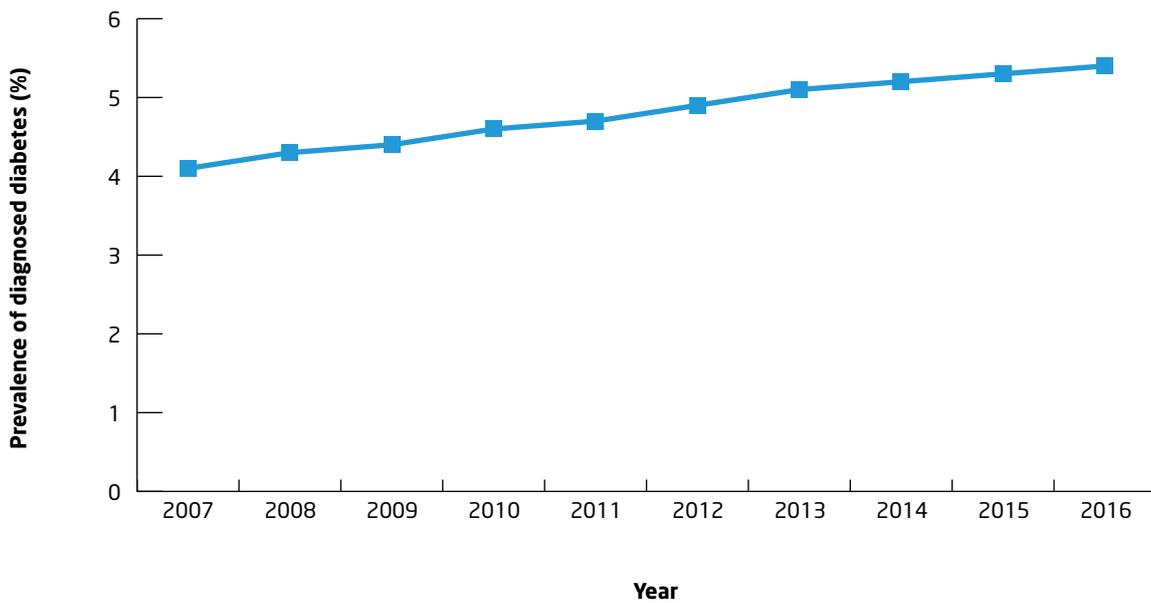
HEALTH OF THE NATION SNAPSHOTS

This section builds on the overall picture described in the preceding section by picking out some more detailed snapshots of Scotland's health - each of which serves to illustrate an ongoing challenge, emerging concern, or success story for Scotland's health.

The intention of these snapshots is to provide a detailed insight into selected trends and to provoke discussion about how we might use these data to improve the health of our nation.

TYPE 2 DIABETES AND OBESITY

Figure 18. The prevalence of diabetes in Scotland has risen in recent years: most of this increase is due to type 2 diabetes.



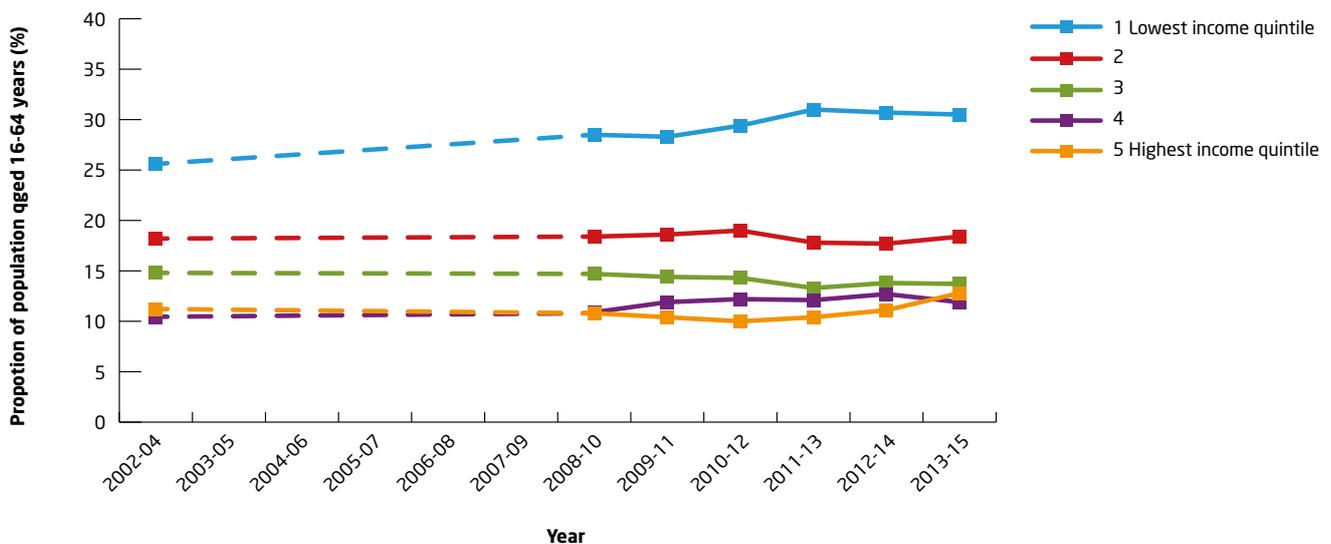
Source: Scottish Diabetes Survey 2016

- The prevalence of diagnosed diabetes in Scotland has risen in recent years⁷⁸, from 4.1% in 2007 to 5.4% in 2016 (Figure 18). This may be an underestimate of the true prevalence, as many people with diabetes go undiagnosed. Type 2 diabetes accounts for around 85-90% of cases of diabetes, and for the majority of the observed increase in prevalence over time.
- The main contributor to this upward trend is likely to be due to poor diet (specifically excess energy intake), low levels of physical activity and the resulting increase in levels of obesity. However, the ageing of the Scottish population, and better detection and increased survival of people with diabetes, are also likely to play a role.
- In 2016, 65% of Scottish adults were overweight, including 29% who were obese.⁷⁹
- Obesity among adults has increased over time since 1995, though has been more or less stable in more recent years.⁸⁰ Since 1995, average BMI has increased across the whole population, but the biggest increases have been seen among those who already have a high BMI.
- For both adults and children, people living in the most deprived areas are more likely to be overweight or obese than people living in the least deprived areas.⁸¹ Among children, the gap in obesity risk between the most and least deprived areas has widened over the last twenty years.⁸²
- Rising levels of obesity in the population are caused by many factors, including changes in the food system, work, transport and the wider economy. This "obesogenic environment" requires a population-level response to reduce obesity and associated harms, like type 2 diabetes. An updated strategy on diet and obesity will be published by the Scottish Government in 2018.

INEQUALITIES IN MENTAL HEALTH

- Inequalities in mental health are persistent in Scotland and there is some evidence they have widened in recent years.
- Data from the Scottish Health Survey suggest that the prevalence of possible mental health problems has risen significantly among the poorest fifth of working-age adults over the last 15 years, whilst remaining relatively stable in other socioeconomic groups⁸³ (Figure 19).

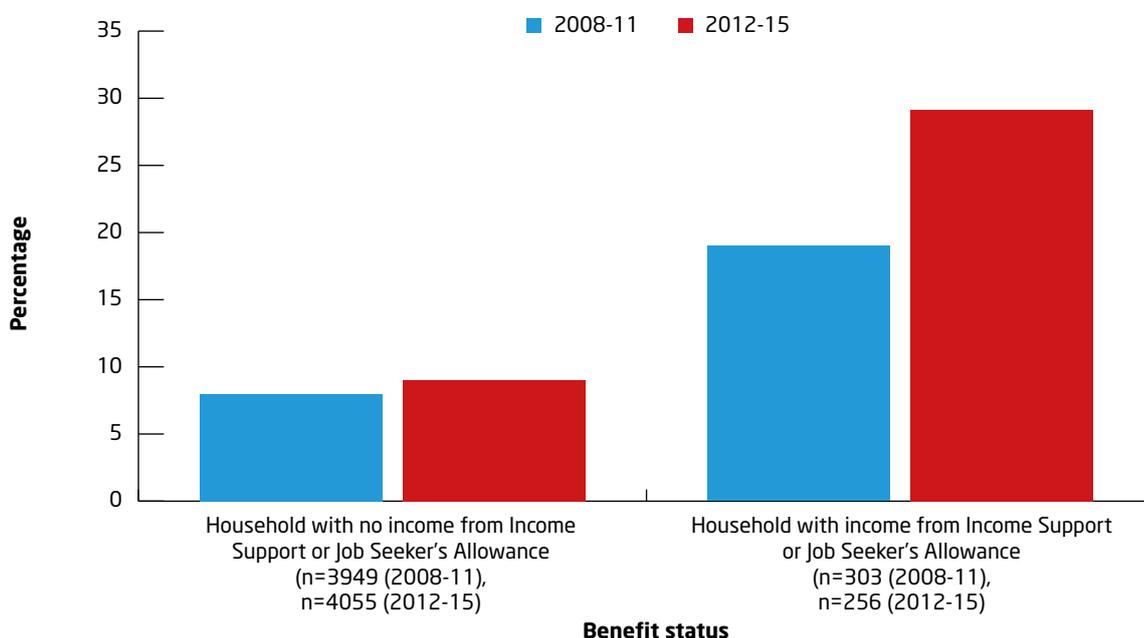
Figure 19. The percentage of working-age adults aged 16-64 with a GHQ-12 score of 4+ (indicating possible mental health problems), has increased in recent years among people from households in the lowest income quintile, but not among those in higher income households.



Source: Scottish Health Survey, 2016

- The Scottish Health Survey also shows that mental health among young adults has deteriorated since 2012, with the percentage with a possible mental health problem increasing from 13% to peak at 22% in 2015. In contrast, the proportion of the total working-age population with a possible mental health problem has remained fairly constant. This trend might partly be explained by an increasingly flexible and insecure labour market and recent changes to social security benefits, both of which have particularly affected young adults.⁸⁴
- Since 2008, the Scottish Health Survey has collected data on the prevalence of anxiety among the adult population in Scotland. Examination of these data before and after the new welfare sanctions regime were introduced indicate a potential adverse impact on mental health (Figure 20). Among adults living in households in receipt of Job Seeker's Allowance (JSA) or Income Support (IS) in 2008-11 (before the change), 19% had moderate to severe anxiety symptoms. Among those in a similar position in 2012-15 (after the change), the proportion was 28%. Adults living in households not receiving JSA/IS, who were unlikely to be affected by these changes, showed only a minimal increase in anxiety symptoms over the same period.
- Together these findings suggest that mental health has worsened in recent years amongst those most affected by economic and labour market insecurity, and by welfare reform. This highlights the importance of a secure household income and good work to mental health and wellbeing.⁸⁵

Figure 20. The prevalence of moderate to high anxiety has increased markedly in recent years among adults living in households receiving income from Income Support or Job Seeker's Allowance, but only slightly among those who do not. This has been linked to changes in the benefit system.



Source: Scottish Health Survey, 2016

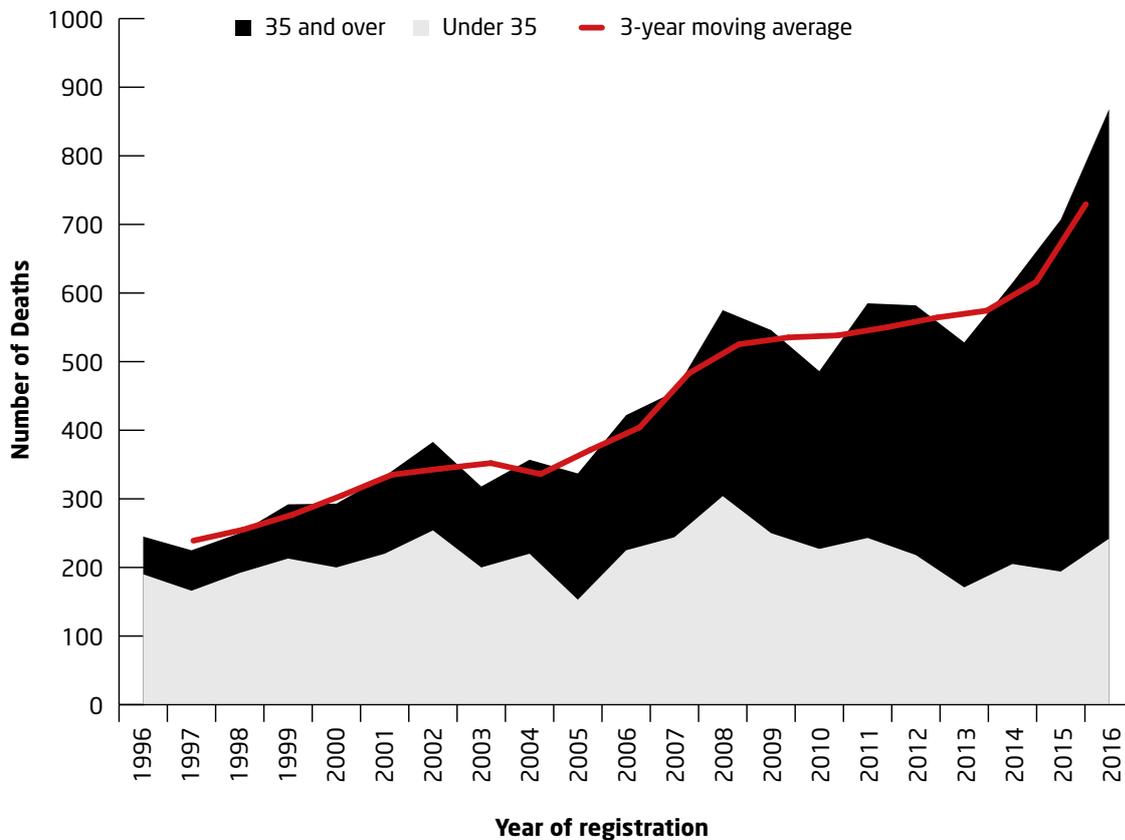
SMOKING

Smoking remains the biggest individual-level risk factor for morbidity and mortality in Scotland. Around 10,000 deaths (around a fifth of all deaths) and 120,000 hospital admissions in Scotland are smoking related. Smoking kills half of all regular smokers, and people in our least well-off communities are three times more likely to smoke than people in our best-off communities. This distribution and the high cost of smoking (averaging out at over £2,000 per year per smoker) has a significant on-going social, economic and health inequalities impact.

Scotland has made great progress in protecting people, especially children, from the harms of tobacco smoke and in smoking prevention – halving the rate of reported exposure among children to second hand smoke and reducing smoking levels among school-age children to an all-time low. Greater emphasis is now needed in encouraging more smokers to quit. The challenge is to get more smokers to seek support from NHS stop-smoking services - where their likelihood of success is more than doubled compared to trying to quit without support. Beyond encouraging more smokers into services we also need to ensure there is consistency of treatment options and consistency of advice available across Health Boards and their community pharmacies – 70% of all smokers using NHS services do so through community pharmacies.

DRUG-RELATED DEATHS

Figure 21. Deaths caused by the acute effects of drugs have risen in recent years, and in 2016 were at the highest level ever recorded in Scotland.



Source: National Records for Scotland

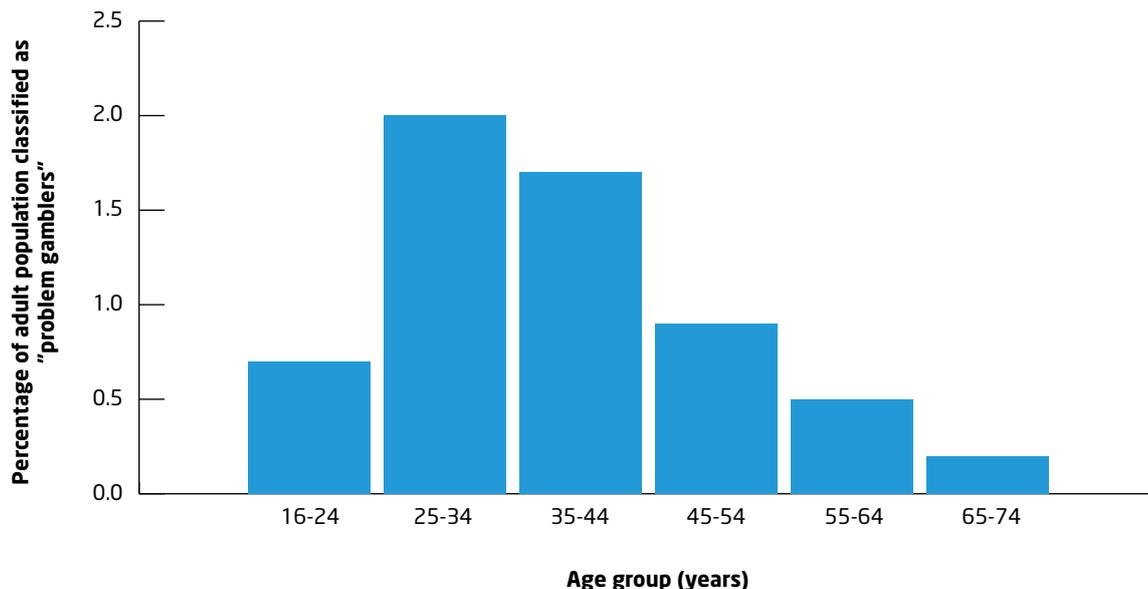
- In 2016, there were 867 drug related deaths in Scotland, 23% higher than in 2015 and the largest number ever recorded (Figure 21)⁸⁶. (This definition relates only to deaths caused by acute effects of the drug itself, and does not include deaths from secondary complications or long-term conditions associated with drug use, such as thromboembolic disease (blood clots) or blood-borne viruses.)
- Numbers of drug related deaths have doubled in the past ten years (from 421 in 2006) (Figure 21).
- There is a strong association between socioeconomic disadvantage and drug-related death: the most recent data available show that, between 2009 and 2014, 53% of deaths were among people living in the 20% most deprived neighbourhoods.⁸⁷
- In 2016:
 - Over two thirds (68%) of these deaths were in men.
 - Heroin and/or morphine were implicated in, or potentially contributed to, the cause of 473 deaths (55%); one or more opiates or opioids (including heroin/morphine and methadone) were implicated in, or potentially contributed to, 765 deaths (88%).
 - Most deaths involved more than one substance. In particular, benzodiazepines (for example diazepam, diclazepam and etizolam) were implicated in, or potentially contributed to, 426 deaths (49%).
 - Scotland's drug-death rate (relative to the number of people aged 15 to 64) is higher than those reported for all the EU countries (though there are issues of coding, coverage and under-reporting in some countries). Scotland's drug-death rate per head of population is roughly two and a half times that of the UK as a whole.

■ The average age of those who have died has increased over time, reflecting the known ageing profile of people with problem drug use (Figure 21). This change in demographic profile has important implications for how health and social care services

are developed and delivered for this population.⁸⁸ A refreshed strategy for drug and alcohol treatment in Scotland is due to be published by the Scottish Government in summer 2018.

GAMBLING

Figure 22. About 1% of the Scottish population over 16 years of age are estimated to be problem gamblers. The prevalence is highest among young men.

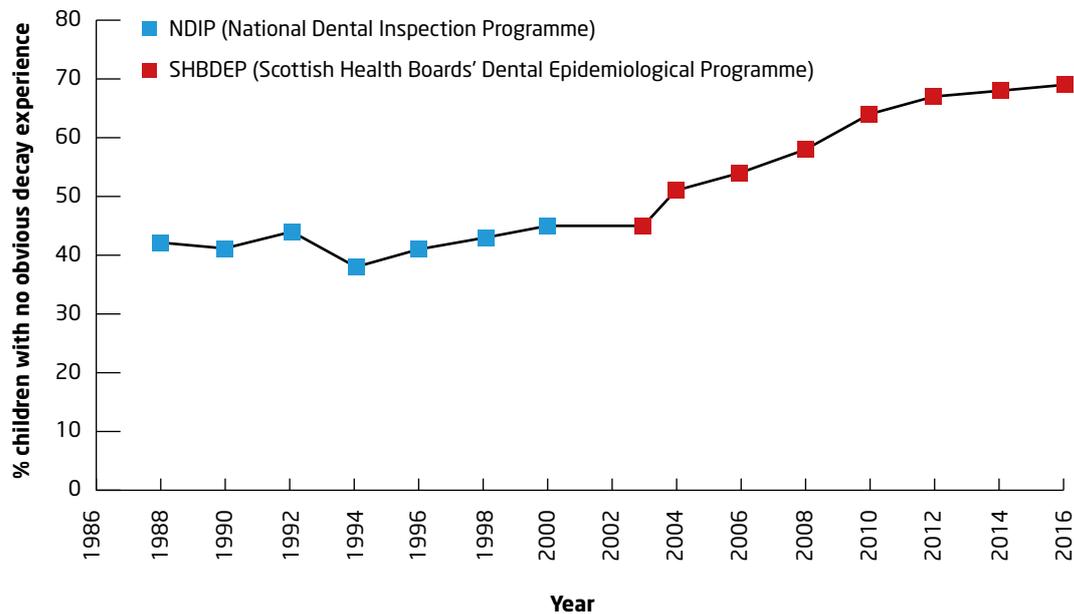


Source: Scottish Health Survey 2016. Estimates based on either Problem Gambling Severity Index (PGSI) or Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association, Fourth Edition (DSM-IV) scores

- In 2016 two thirds of Scottish adults reported that they had spent money on gambling within the previous 12 months.⁸⁹
- Many people gamble without experiencing adverse consequences, but others experience a range of health harms including depression, anxiety and poor physical health. People can also experience a range of other harms detrimental to health and wellbeing, such as financial difficulty and distress and relationship breakdown. Problem gambling is defined as "gambling to a degree which compromises, disrupts or damages family, personal or recreational pursuits".
- In 2016 1 in 100 Scottish adults (1.0% of the adult population, or around 45,000 people) were problem gamblers, based on two standard measures⁹⁰ (Figure 22). This rose to nearly one in 30 (3.4%) among men aged 25-34.
- A further 1.2% (around 54,000 adults) were likely to be at risk of gambling problems, based on a standard risk questionnaire.
- The prevalence of problem gambling in 2016 was highest among those in the lowest fifth of incomes and those in routine or manual occupations.
- There are no data available on gambling among children under 16 in Scotland: a recent survey in England and Wales found that 16% of 11-15 year olds reported having gambled in the previous week and that 75% had seen gambling advertising on TV.⁹¹

CHILDREN'S ORAL HEALTH

Figure 23. The percentage P1 children in Scotland with no evidence of dental decay has risen substantially between 1988 and 2016.



Source: National Dental Inspection Programme, 2016

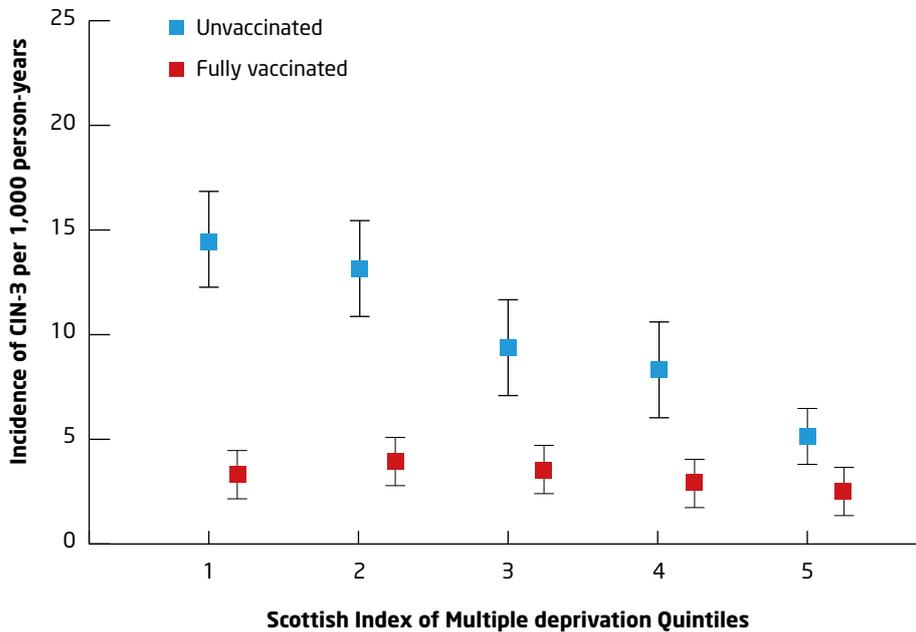
- Children's oral health in Scotland has dramatically improved over the last 15 years, in contrast to several other indicators of child health (Fig 23).
- The reduction in dental decay has been shown to be the result of a national child oral health improvement programme⁹², which started in 2000 and was formally launched as "Childsmile" in 2005.
- Childsmile combines universal provision with targeted services for those most at risk, including: nursery toothbrushing and distribution of free toothbrushes and toothpaste; nursery and school fluoride varnish application; referral from health visitors to dental health support workers; child-friendly dental care delivered to children in dental practice. It involves multiple partners across health, education, and community settings – with robust evaluation. The success of the programme is dependent on the contributions of children, parents/carers, education staff, and dental teams.
- In particular, the supervised toothbrushing programme component of Childsmile, which is delivered to almost all nurseries in Scotland, has been shown to provide substantial savings to the NHS in reduced treatment costs⁹³ – the programme "broke even" within three years and by eight years the expected savings reached over two and a half times the costs.



- However, challenge of health inequalities remains – with 45% of five-year-olds from the most deprived communities (SIMD 1) still experiencing obvious dental decay.
- Childsmile has been recognised as a world leading approach, with elements of the programme adopted internationally.
- The forthcoming national Oral Health Improvement Strategy will provide further opportunities to continue this work and address these challenges.

HPV VACCINATION PROGRAMME

Figure 24. Women who have received a full course of the HPV vaccine show much lower rates of pre-cancerous changes in the cervix (CIN) than their unvaccinated peers. Vaccination has also reduced socioeconomic inequalities in rates of pre-cancerous changes.



Source: Cameron et al (2017)⁹⁴. Scottish Index of Multiple Deprivation (SIMD) quintiles. SIMD 1 represents people living in the 20% most deprived areas in Scotland, whilst SIMD 5 represents people living in the 20% least deprived areas.

- Cervical cancer disproportionately affects women from lower socioeconomic backgrounds. A human papillomavirus (HPV) vaccination programme was introduced in Scotland in 2008 to reduce infection with HPV and HPV-induced cervical cancer.
- HPV vaccine is offered to girls in secondary school with multiple opportunities for catch-up of missed doses, ensuring that uptake is high across all socioeconomic groups.
- By confidentially linking data on vaccination uptake with records from colposcopy clinics, it has been shown that women in Scotland who received the HPV vaccine had much lower rates of pre-cancerous changes in the cervix (cervical intra-epithelial neoplasia; CIN)⁹⁵.
- The effect of the vaccine is especially marked among more deprived socioeconomic groups, who had previously had the highest burden of disease: among those vaccinated, the social gradient in the most severe pre-cancerous changes has largely disappeared (Figure 24).
- These welcome results suggest that the HPV vaccine is helping to reduce inequalities in cervical cancer risk across Scotland. However, since the vaccine does not protect against all types of HPV, women who've been immunised still need to go for regular screening (smear test) from 25 years of age.

HIV PRE-EXPOSURE PROPHYLAXIS

- Pre-exposure prophylaxis (PrEP) refers to the use of an anti-retroviral combination drug to prevent HIV infection. Several large international studies have demonstrated a substantial reduction in HIV transmission among those using PrEP.^{96, 97}
- PrEP became available on the NHS in Scotland in July 2017. PrEP is being prescribed to individuals at the highest risk of HIV infection as part of a comprehensive approach to HIV prevention, in tandem with regular HIV testing and safer sex practices.
- Men who have sex with men account for the majority of those eligible for PrEP in Scotland: estimates suggest that the number eligible is around 1700 (range 1500 to 1900). Based on this, it has been forecast that approximately 1000 people (range 880 to 1100) may come forward to commence PrEP in Scotland in the first 12 months of implementation.⁹⁸
- The use of PrEP could transform the epidemiology of HIV infection in Scotland. Efforts are now underway by a national co-ordination group to ensure equity of access across Scotland, through work on education and awareness, clinical service provision, and monitoring and evaluation.

WHOLE-GENOME SEQUENCING

- Whole Genome Sequencing (WGS) is a technique that allows the entire DNA sequence for a particular person or organism to be determined. Recent advances have reduced the time and cost associated with WGS to a point where it is now becoming feasible in areas of clinical practice to inform diagnosis and to target treatment.
- The **Scottish Government has invested in the Scottish Genomes Partnership** – a collaboration between Scottish Universities and the NHS – to take forward genomic research programmes on rare diseases and cancers and to pilot, in association with Genomics England, Whole Genome Sequencing of patients with undiagnosed genetic conditions to help provide a diagnosis. Enrolment of Scottish patients and their families to defined clinical criteria began in May 2017, delivering on a commitment of the 2014 Scottish Government Rare Disease Implementation Plan **“It’s Not Rare To Have a Rare Disease”** to explore whole genome sequencing for diagnosis of rare diseases. At the request of the CMO, the Scottish Science Advisory Council is providing advice and a report during 2018, on the development of genomic medicine in Scotland. This will inform future activities and a Scottish strategy for the organisation and delivery of genomic medicine.
- In the health protection setting, WGS can be used to more precisely identify infections and microbial contaminants and minimise much of the uncertainty associated with to the prevention and control of communicable disease. Since 2015, Health Protection Scotland and the Scottish Microbiology Reference Laboratories have worked closely to develop plans to implement and embed the WGS technology in the national public health microbiology services.
- Examples of the application of this technology include detection of the source of contaminated foods, improvements in the investigation of healthcare associated infection incidents, and analysis of antibiotic resistant “super bugs” that previously would have required much more time and resource to resolve.
- As a result of this preparatory work, WGS microbiology reference services for VTEC and Salmonella began in autumn 2017. Progress with the implementation and gains achieved through the introduction of pathogen genomics across the Scottish microbiology reference laboratories will be included in future annual reports.

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