Scotland – small country, big ideas

Imagining the future...

Creating the future

Active, healthy citizens

Thriving communities

Services fit for the future

Views from members of the Health and Social Care Alliance Scotland
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THE ALLIANCE VISION

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The Health and Social Care Alliance Scotland (the ALLIANCE), along with many of our 600 members, have long argued for transformative change in health and social care. Recent years have seen growing consensus on the need for radical change. What is less clear is how we are going to quicken the scale and pace of progress towards models of health and social care that are truly fit for the future.

Attempts to alleviate stubborn health inequalities and find better responses to an ageing population and rising social need are set against a backdrop of mounting financial pressures and reductions in public spending. Disabled people, those living with long term conditions and unpaid carers are feeling the impact of rising living costs (with wages failing to keep pace), welfare reforms and cuts to – or increased charges for – many of the supports that enable them to enjoy their basic rights to health, independent living and work.

How then, do we ensure that the health and social care of the future supports an inclusive Scotland in which we are all able to flourish and contribute?

While there are no simple answers, the following set of think pieces offer rich insight into some of the essential ingredients for shaping a fairer, healthier future Scotland.

It is clear that the Christie agenda remains the key touchstone for many, and the foundation upon which we have built the 2020 Route Map to the Vision for Health and Social Care, along with legislation on self-directed support, integration and community empowerment. Engrained throughout this suite of policies are co-production, asset-based approaches and ‘people powered health and wellbeing’.

Our contributors are clear that these must become ‘business as usual’ and translate into real and positive change in people’s lives.

Many of our members remain at the vanguard of reshaping health and social care. We read here of the crucial role played by the third sector in redesigning services around the principles of human rights and greater connection between statutory and community-based supports.

It is clear too that a healthy future spans far broader issues, including communication, transport, housing and tackling the increasing impact of loneliness, particularly on our older citizens. Perhaps the most urgent issue of all is that of inequality, with poverty and health inequalities continuing to blight our society and undermine the lives of far too many.

Whatever the future of Scotland what matters most is that our citizens and communities are recognised as our biggest asset, both in meeting the challenges we face and in shaping how we do that. The ALLIANCE is founded on the strength, value and power of lived experience and we look forward to continuing to work with our members and others to ensure we apply our collective energies to shaping the fair, inclusive future we want.
Scotland – small country, big ideas

Imagining the future…

Views from members of the Health and Social Care Alliance Scotland

The ALLIANCE Portfolio

Route Map to the 2020 Vision for Health and Social Care
The future is not some place we are going, but one we are creating.

“The paths to it are not found but made, and the activity of making them changes both the maker and the destination.”

John H Schaar, Political Theorist, Science Advisor, Nixon

We are living through a change of age. The fundamental precepts by which we live are changing. We live in a world of increasing complexity and rapid change which is difficult to understand and impossible to control. There are an increasing number of intractable challenges which will not yield to what we know how to do. The strain on our institutions is palpable. How are we to proceed?

Business as usual will not be merely inadequate in supporting human wellbeing, but might also be destructive, supporting ways of life that are psychologically, culturally and environmentally unsustainable. How do we overcome the limitations of our current frameworks and resistance to change? How are we to make the future?

The turbulence which a change of age brings normally evokes three kinds of response.

Denial/Resistance
In this response the possibility of fundamental shift is denied. Explanations, for example, of the failure of policy and activity to effectively handle emergent challenges focus on the shortcomings of effort within the existing paradigm – the targets were not quite right, our efforts must be redoubled etc. In this view there is room for only a single
truth and if my truth is correct, anything which differs from it must be wrong. This approach is often accompanied by efforts to reinforce boundaries which are patrolled with increasing severity until they can hold no longer.

Nihilism/Collapse

A second type of response to change is that of nihilism. If the denial response is characterised by insistence on a single truth, nihilism is characterised by the lack of any coherent story at all. This response often contains a dose of cynicism and defeatism. Life becomes more chaotic as social norms, identities and values collapse along with previously clear boundaries. There can also be wild swings in behaviour in such responses contributing to further incoherence. In individuals, this can give rise to despair and self-destruction. At the level of society, solidarity is attenuated, common bonds fragment as individualism comes to the fore. There are also instances of the collapse of societies and civilisations.

Transformation

Both denial and nihilism are associated with decline. Situations which hold the possibility of collapse also hold the possibility of transformation in the same moment. In a world of uncertainty and shifting identity it calls for a willingness to engage when outcomes are impossible to predict and a willingness to create culture together anew in ways which no individual or single group could. To pursue the latter, processes need to be developed which allow for questioning, discussion, testing, reconsidering and learning - until systems (at every level) are developed which better support life in the new circumstances. How?

1 We would do well to start by admitting the extent of our ignorance and the conditional nature of what we do know, otherwise we will continue to use outdated methods as the only options.

2 Learning how to become hospice workers for the dying culture and midwives for the new simultaneously will help us to keep those aspects of current arrangements which will help to make the transition, give up those which won’t and identify new perspectives and associated activities which take us in the direction of the future we desire.

3 In this territory a compass will be more useful than a map. Its points should represent our highest values and our work should be guided by them. I suggest abundance, mutuality, diversity, hope, beauty, person centred, co-created, and integrative of life, ecological, ethical, creative and beautiful as contenders for compass points – just to get the debate started!

4 Develop national infrastructure which supports transformation. The International Futures Forum is working on a National Infrastructure for Transformative Innovation (NIFTI) and would like to join with others too.

These are simply some suggestions which might help us get started. The best way to predict the future is to make it.
When we are in times of pressure and what is indeed a change of age, it’s easy to feel overwhelmed, to struggle to see a future that offers hope. We know people delivering services see demand growing but many are locked into the daily pressures too much to see the way through.

We are dealing with complex systems, with the wicked questions of health and wellbeing and much though I would love to produce the rabbit out of the hat and say “apply this magic formula and you too can do this”, no such solution exists. And beware of people who tell you it does.

Transform

But what I do know is if we apply some fundamental values and principles and proactively embrace the future we will improve wellbeing for people and communities and find the way to offer person centred relational health and social care as equals in the process.

To begin well we need to start from assets not deficits. We need to see that increasing health costs and numbers of older people does not need to be seen as a problem and in many ways is a success story. But what it does need is fresh thinking and approaches.

Let’s also build health with communities; in listening not telling mode and enable the community connectors who can build the assets and the wellbeing together. To do that...
we need, as professionals, to let go of control and experience the relief as we recognise the burden we have carried in the existing paradigm.

**Connect**

Let’s be open and honest in our communication within natural communities (of geography or of interest), to build empathy and understanding of the reality. Let’s work with the assets and inner motivations and listen to the more radical ideas and invest in improvement.

Put people at the centre of care and decision making, both at a personal and system level and the care and service will develop emergently and so respond to changing need.

Can we all set aside hierarchy, ego, knowing and fixed patterns and instead support and enable people to create their own solutions without barriers to progress? In that way we will all become partners in the process in an ongoing way.

Health and independent living are human rights, as are the determinants of good health and the support people need to be included as citizens within our communities. A human rights based approach also helps us shift in thinking, for example viewing older people as individuals with rights and indeed assets. That shift in thinking flips our view of health and care.

I urge us to trust more, measure less, let go of knowing and be willing to discover, accepting that staying the same or trying harder to do the same isn’t working.

**Learning**

Let’s be free to learn from others, especially those who bring lived experience and practice based evidence, not just evidence based practice. Recognise that we need to let go of the ‘fix it’ model of health and instead focus on how to enable our inner capacity for healing and wellbeing. These innovators exist already let’s listen to them and trust them.

Support for people with long term conditions to self manage needs to be the norm, putting power into the right hands.

We need to be willing for us all to get it wrong and be honest, but keep learning and try again and again and again...

**Love**

I see how exhausting it is to keep trying to make it work even when we know that it’s broken. We will only release ourselves from that if we recognise that health and care is all about relationships; between individuals, in teams, in communities. That alongside a future of more equitable relationships between health and care professionals and those they serve, there needs to be compassion, kindness and love, for this will provide the magic for the new dance.

I would love to dance into that future... you dancing?
We must not let our past, however glorious; get in the way of our future.

Charles Handy

In order to look forward it sometimes helps to reflect on the past. I have always been struck by the foresight of our predecessors who set up the World Health Organisation (WHO) as a force for positive change. In the founding constitution of WHO in 1948 they created a clear definition of health:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

However it seems that we have spent the last 66 years developing and delivering a health system that seeks to deal with reducing and treating illness whilst separately delivering a welfare and social care system that responds to social and wellbeing crises.

In both cases our services and systems have been set up to respond to need at a time of difficulty, illness or crises. In the future we need to clearly understand and deliver on the presumption of preventing crises of health and wellbeing and promoting opportunities to access support early.

Ideally, by 2025 we will focus as much on resilience and wellbeing as we currently do on illness/social crises.

We have already set down some markers in legislation: Health and Social Care integration, self-directed support and community empowerment. Alongside the legislation we have clear supporting policy such as the ‘Christie’ principles, a 2020 vision for health and social care and


If we look forward to 2025 how much will have changed?

Hopefully we will have a new understanding of the relationship between the state, citizens and communities (regardless of the outcome of the independence referendum).
This understanding will reframe the original notion of the welfare state and shift the emphasis from the paternalistic, top-down, ‘cradle to grave’ public services that react to critical need and crises. Instead we will have new relationships with citizens and communities where the approach is about co-creating and utilising strengths and assets.

If we genuinely believe that ‘more of the same will not work’ (Changing Lives 2006), then the way in which we think, act and behave will need to change. Each of the transformations listed below will enable us to achieve a world that in 2025 offers inclusive communities, ways of working/engaging that supports wellbeing and where we recognise and utilise the strengths and assets of people and communities.

- From passive recipients of services to being students of our own wellbeing.
- From care providers to coaches and educators.
- From providing services to providing service (alternatively this could be framed as moving from being wholesalers of services to being retailers, where customer service and satisfaction is paramount).
- From measuring service outputs to measuring personal outcomes.

Two fundamental principles must support these transformations:

- **Trust:** trust people and communities to do the right thing and stop simply trying to do things right for people and communities.
- **Devolution of power and decision making:** we need to ensure that the rights of choice and control as defined in the Social Care (Self-Directed Support) (Scotland) Act 2013 are realised by offering people real choice and control over their care and support. Communities also need to be empowered to make decisions that are right for them.

Will communities continue to be seen as geographic communities? By 2025 we might have to rethink what we mean by community as many people are/will be part of online communities and we spend as much time in our work communities as we do in the communities in which we reside.

Could it be that by 2025 we have legislation that gives communities more control of budgets and services? This legislation could take the options of the Self Directed Support Act and allow communities to self-direct public services in a variety of ways.

In 2025 towns and communities could be working towards their ‘Wellbeing Community’ quality mark. This would be awarded where communities have sought to promote and generate activities that focus on connecting, listening and supporting one another’s wellbeing to ensure more resilient connections within their area.

Technology will play a significant part in our lives and we will have online tools for everything. The use of technology has the power to enable people to participate in ways we have not yet fully grasped or understood. It will streamline communication and bureaucracy. Ideally we should have moved to a position where individuals hold all the information about themselves (in safe/secure online environments) and give appropriate access to services and professionals for the information they need. This would transform how we currently manage case files and information. It will reduce the need for multiple questions and assessments by enabling and trusting the person with their own information rather than the current issues of data protection and confidentiality which often hinders communication between people and services and leads to duplication of effort.

So… to the future and beyond……
Start with what matters

Big ideas need people with passion, commitment and energy and most of all a belief in themselves to bring them to life.

Whatever way we vote in September we couldn’t be at a more opportune time for the future of health and social care in Scotland. We have huge and explicit aspirations for the future.

The language of assets, co-production, personalisation and citizens at the heart of decision-making are the new “must do” words for us all.

We have a Cabinet Secretary who is not only responsible for our nation’s health but has a remit for the wellbeing of the citizens of Scotland. And an aim to shift the current image of Scotland as the sick man of Europe to that of a country where, not only is there less illness, but our citizens feel genuinely happier, healthier and more successful; where more of us feel that life is going well.

Such a fundamental shift in self and national concept needs to find local and meaningful expression.

Big ideas need to find ways to become concrete to avoid cynicism and tokenism in their delivery.

The real opportunity and challenge that we face involves a major shift in our collective mindsets at an individual, community and national level – from a tendency to focus on what

isn’t working (problem, disability or deficit), to one that starts to look out for evidence of our nation’s capacity and potential, to search for opportunities to grow our belief in ourselves and our communities.

Many people see the area that I have worked in most of my working life in terms of its deficits – its poverty, ill health and lack of aspiration rather than as a community full of people with huge capacity and resources already providing all sorts of informal support to each other.
The people that my organisation works alongside are often described in terms of their disability, needs and vulnerability. Indeed people do need help and assistance to live their day to day lives but what I also see, every day, are the ways that people give back to their communities in all sorts of immeasurable ways. I see the difference having the opportunity to do so makes to people’s confidence and sense of self-worth.

However, I have also witnessed the innumerable times when people go on to internalise negative self-concepts and the damage this has on people’s self-image and confidence which reinforces a sense of helplessness and dependency.

We need to start small and with the things that matter most to people. There is no point in helping people stop smoking, or eat less if what matters most is finding the energy to visit a grandchild or walk a dog. Small successes breed confidence and a belief that more is possible.

This means getting much better at having good conversations with people that help identify what is most important to that person to have a good life.

Looking to the future we need to become transformationally better at believing that people and the communities they live in really are their own best experts, and even in the face of extreme adversity can and do find ways of coping and managing.

We need to get better at noticing and celebrating every little indication however small, that people and the communities they live in have huge internal and other resources waiting to be untapped.

This paradigm shift requires us to start looking for evidence that life is indeed going well.

At the same time we need to stop trying to change or sort people in ways that are important to us.

Shifting our mindset means assuming competence and contribution in the people we work alongside and believing that together we can build a stronger healthier nation.
Digital Scotland: future-proofing the third sector

The Scottish Government has a bold ambition: Scotland should be a world-leading digital nation by 2020. It’s hard to argue against that - independent or not it’s clear Scotland needs to embrace new technology if we are to have a truly diverse, robust economy. The Scottish Government’s ‘Digital Future’ strategy outlines four key strands: connectivity, digital public services, digital economy and digital participation. The Scottish third sector has a pivotal role to play, particularly around digital participation and public service delivery. But without a fundamental shift in thinking there is a danger the third sector will be left behind – along with vast swathes of the population.

30% of Scots don’t have basic digital skills. That figure rises to 50% of people with disabilities and 60% where the individual has no qualifications. 15% of Scots have never used the internet. A Citizen’s Advice Scotland survey found 36% of their clients have never been online. These stark figures highlight a massive societal gap that needs to be addressed if we are to achieve that 2020 vision of a digital Scotland. Access to physical technology and connectivity, particularly in rural areas, is important. But for me they’re not the big issues. We need to ensure people have basic skills needed to get online and embrace the internet. That word ‘embrace’ is key. Oxford University looked at why people choose not to use the internet in their everyday lives – 82% of respondents were ‘not interested’. Researchers found no evidence that these people are restricted from going online. They simply don’t care. For many older, disabled and unemployed people their first foray into the digital world will be mandatory online-only benefits claim forms – hardly an inspiring start. In a sense digital
inclusion is more about social barriers than technological ones.

Recent research on digital exclusion from the Carnegie UK Trust recommends that ‘trusted intermediaries, such as voluntary workers, community development workers... can help to deliver the personalised, differentiated approach that is needed to help different groups of citizens in Glasgow to get online’. So third sector staff and volunteers will be key in ensuring the digitally excluded are skilled and enthused but it’s also worth thinking about that other strand of the Scottish Government’s digital strategy - digital public services. I believe the third sector can deliver innovative, effective services through a ‘digital-first’ approach. Of course we will always need face-to-face interaction with service users but let’s not use digital exclusion as an excuse for inaction. So could an Argyll & Bute counselling service save money and reach hundreds more isolated individuals if it allocated half its travel budget to video technology rather than the environmentally-unfriendly, time consuming practice of counsellors driving all over the region?

My experience on Foundation Scotland’s grants committee, chairing other funding panels and working with Scottish charities in my role at Third Sector Lab tells me that two fundamental areas need to be addressed to get the voluntary sector ready. First we need a skilled workforce ready to ask how digital technology can help us deliver cost-effective services that make a real difference to the lives of Scottish people; we need digital champions within every Scottish non-profit. Secondly we need funders to understand the difference digital can make and put their money where their mouth is. We don’t necessarily need dedicated funding streams – digital should permeate all areas of the funding landscape. We also need to ensure grants officers have the skillset to objectively assess tech-based project applications from charities and social enterprises. Once we make that shift I believe the Scottish third sector can lead the world in digital media for social good.
We know the future for health and social care in Scotland will be, and must be, different. There is a ferocious bustle of reform activity – reshaping care, integration, self-directed support, joint strategic commissioning – but it isn’t yet clear how these will all work together. There’s a broad consensus on the direction of travel, but it’s not yet clear where we’re going; or if the gears are working as well as they should when we face sharp bends or bumps in the road.

The Christie Commission issued a clarion call for more preventative services, and there are some excellent examples across Scotland, from lunch clubs to walking groups. But if everyone who needs such support in later life is to get it, no matter where they live or what their income, there must be a more sustained investment in such services and a more robust means of recognising and measuring their value. Too often, we hear from our member groups delivering preventative services that, as demand increases, their income is falling or less certain. The desire to protect core services in a time of austerity means prevention struggles even more for resources, with the Change Fund seen as little more than a temporary sticking plaster.

“Social prescribing” – one of the latest buzzwords – will be meaningless if the community services aren’t there to refer to.

Often the people who need preventative services most are stymied by lack of access to transport. If you are remote from or unable to use public transport, your free bus pass will be of little benefit. Following years of underinvestment, the community transport services people need are wholly inadequate. A recent injection of £1 million by the Scottish Government for community minibuses is welcome, but falls far short of a sustainable strategy to expand community transport to meet growing demand. Minibuses and social clubs might not seem at first glance like vital components of a sustainable 21st
century health care system. But, without them, isolation and loneliness, ranked twice as damaging to health as obesity in a recent study, will continue to diminish the wellbeing of our older population.

There have been genuine efforts to personalise services, including the recent legislation for self-directed support. The priority now must be to ensure such measures translate into meaningful improvements in people’s experiences, and are not hollowed out by smaller budgets or higher charges for service users, and that they have the information and support they need to make effective choices about their own care.

The concept of personalisation should also inform how we develop preventative services. One example of how this can be done is Men’s Sheds. These began in Australia, following recognition that many older men find mainstream older social and activity opportunities unappealing, and consequently become either isolated or over-reliant on the pub for social support. Age Scotland is now supporting establishment of Men’s Sheds across Scotland, places where older men can enjoy camaraderie as they work together on projects that interest them, and that are very often of wider community benefit too. If we want people to lead active and healthy lives as they age, and increase their chances of a high quality of later life, such tailored opportunities must be readily accessible across the country.

With the Default Retirement Age gone and the State Pension Age rising we must also rethink the concept of retirement, to ensure that more of us find the later stages of our careers fulfilling and enjoyable. Stopping work should be seen less as a cliff and more as a process of gradual change from productive employment to active later life.
Recent changes to legislation and policy are to be welcomed aiming as they do to improve the quality of life for people in Scotland.

The 2020 Route Map supports a ‘commitment to shift the balance of power to... individuals and communities’. It goes on to state that ‘working in partnership is fundamental to achieving progress in each of the priority areas – partnership... with people.’

The Scottish Independent Advocacy Alliance (SIAA) supports all of the stated aims of, and the principles that underpin the Self-Directed Support Bill and the Public Bodies legislation. However what legislation says and what happens on the ground do not always match up. We believe there is a real need to ensure that everyone has the opportunity to contribute both to a national planning framework and to decisions that directly affect their own lives.

How can those members of our society who are most excluded, most vulnerable and least heard be supported to be fully involved in planning and decision making? Access to independent advocacy is a vital factor in ensuring that all members of our society are as fully involved as possible and as they wish to be in such planning. Advocacy can, for those most vulnerable and excluded members of our society, help to ensure that the stated aims of recent legislation become a reality.

The value of advocacy has been recognised for many years and has played a major role in helping people, who may be vulnerable as a result of illness, disability or other circumstances, to access appropriate help, support and justice... It has also played a part in supporting individuals to be included in their communities, to have their own role and to be a valued member of that community. Collective advocacy has been, and continues to be, instrumental in shaping services in a number of areas.
Advocacy support can have an impact on the health and wellbeing of individuals. Research has shown that the greater control someone has over their lives and circumstances the lower their stress levels. Many people who seek independent advocacy support do so because they believe they have no control over their lives. They may feel that their lives and circumstances are incomprehensible and unmanageable, their options have been severely limited and they feel they have no choice over things even as fundamental as where, how or with whom they live.

Along with the commitment to shift the balance of power to individuals and communities, Priority 1 of the Scottish National Action Plan for Human Rights (SNAP) prioritises increasing people’s understanding of human rights and their participation in decisions.

An important aim of advocacy is to empower individuals to participate fully in decision making, in their lives and in their communities. The process of advocacy aims to restore control, supporting the individual to consider their situation and possible options, helping to make sense of their world. Advocacy can support the individual to speak up or can speak up on their behalf, ensuring that their voice is heard and so gaining, or regaining, control over their own lives and circumstances.

While the right of access to independent advocacy for anyone with a mental disorder is a fundamental part of the Mental Health (Care & Treatment) (Scotland) Act 2003, access for those with other conditions remains patchy. The SIAA vision for the coming years is that of a Scotland where advocacy is freely available for all who need it.

Commissioners should be encouraged to recognise that, for independent advocacy to play the greatest possible role in the improvement of the physical and mental health and wellbeing of the population, there is no ‘one size fits all’ approach. They should be encouraged to ensure that provision allows access to appropriate models of independent advocacy for all who need it when they need it.
Welcome to the Scotland of 2034. It’s a place that’s familiar in some ways, but utterly different in others. Take health, for instance.

Babies born back in 2014 are now entering their twenties. But what does their life look like, compared to their parents’ generation?

Meet Catriona. She’s 20 years old, and she’s going to be your guide to 2034.

“I was born with a heart condition that I inherited from my mum. But scientists worked out which gene was faulty when I was young and, thanks to good advice and treatment I received as I grew up, I haven’t had serious problems. And the news is even better if I have a child of my own. Thanks to advances in gene therapy since I was small, doctors will be able to replace the faulty gene once the baby is born so we won’t ever have to worry about it.

“There are so many other areas of life that have improved over my lifetime. Scotland in 2034 is a smoke-free nation and I can’t remember the last time I saw someone with a cigarette. So there are almost no smokers harming their own hearts or other people’s any more.

“Policies to reduce air pollution have had a really positive effect on health too. No petrol or diesel cars on the roads ensure cleaner air, which mean healthier hearts. People mostly walk or cycle – activities that keep families and communities active together.

“Like most people, I have a pretty healthy diet. I can’t believe some of the stuff that people used to eat – convenience foods and fast foods packed with trans fats, salt and sugar. But these days we cook more with fresh ingredients. Even the big food manufacturers finally realised what their customers really wanted, so it’s easier and cheaper to choose the healthier option.”

For people like Catriona with a heart condition, life has changed a lot in 20 years. More is possible in
diagnosis and treatment than we could ever have believed possible in 2014, much of it thanks to the decades of pioneering research funded by British Heart Foundation Scotland.

Non-invasive imaging techniques are much more sophisticated, detecting and identifying early signs of heart or blood vessel problems, so that doctors can prescribe more effective therapies sooner.

New technologies are also helping people manage their conditions at home. User-friendly personal monitors record their heart and blood vessel function, automatically delivering the information to technicians to help them detect problems or progression of disease at a much earlier stage. Telehealth is a widespread reality and hardly anyone spends time in hospital.

Where treatment is required, biodegradable ‘smart’ stents actually help to repair blood vessel walls before dissolving, while devices like pacemakers are smaller and cheaper, continuously assessing and reacting to the individual patient. People are home a couple of hours after surgery with a care package that makes sure they get any assistance they need to keep well and mobile.

Over to Catriona again: “Of course, we haven’t eradicated heart disease altogether. But there’s incredibly exciting research going on.”

Scientists can now help mend broken hearts, thanks to breakthroughs in regenerative medicine, stem cell biology and tissue engineering. And new medicines can help the heart to repair itself after a heart attack, with bio-engineered blood vessels grown to replace diseased vessels.

Advances in full gene sequencing and analysis have made diagnosis and treatment much simpler for all types of heart and circulatory conditions, including high blood pressure, obesity and diabetes. That’s led to the development of targeted new drugs to make treatment more effective, improving the lives of millions.

And the last word to Catriona: “Scotland in 2034 isn’t Utopia. There’s still a lot to be done to support everyone to make the right choices for their families’ health, and to make sure that all our communities benefit equally from the progress that’s been made. But having come so far in the first 20 years of my life, I can’t wait to see what can be done in the next 20.”
Age, infirmity or disability can all affect our capacity to live independently. But that doesn’t mean that we have to give up our right to choose the way we want to live our lives: to depend solely on the support that can be offered by statutory organisations. Indeed, for a lot of older people it’s the little things that count – a cup of tea, a trip to the shops, being able to attend their GP appointment, the ability to look into the mirror with confidence. It’s being able to do small things like this that will have a positive impact on the ability of older people to live fulfilled and independent lives for as long as possible.

Therefore, as our population of older people continues to grow and as older people become potentially more isolated and vulnerable it is vital that we revisit the ways in which we offer and deliver support.

So what’s our vision?

At the British Red Cross we see the future as one where older people are able to access low intensity support as means of ensuring they are able to live as independently as possible in their own homes for as long as possible.

It is a vision and a philosophy which we believe benefits not only older people but their communities, as well as helping ease pressure on statutory services.

So how do we go about achieving this vision?

At the Red Cross we focus our investment not only in our own qualified health and social care workforce but importantly in supporting communities to become more resilient, developing their capacity and capability to support their ageing population.

Our investment in communities manifests itself in a number of ways ranging from offering people training in potentially lifesaving activities such as First Aid to establishing our own skilled and trained volunteer workforce as well as supporting...
other community based organisations to do likewise.

Locally recruited volunteers are in an excellent position to offer for example, on-going companionship, peer mentoring, emotional and practical support. With their local knowledge and networks volunteers are able to involve their local community in helping to encourage and support activities in groups for older people in isolation. They can contact existing groups and organisations to source activities of interest and encourage local groups to be inclusive, accessible and stimulating.

An added benefit comes from the make-up of our volunteer workforce. Volunteers come from all parts of the community covering all age groups and offer a variety of skills and experience. For some it will be an opportunity to learn new skills and gain work experience which in turn may assist them in securing employment in the future.

But importantly, older people themselves, some of whom have been supported through a crisis, go on to volunteer turning their experience in to a positive way of supporting a peer through similar crisis or in preventing the crisis from happening.

At the Red Cross we are keen to demonstrate how this low intensity support, delivered by a skilled and experienced volunteer workforce can have a positive impact on the ability of older people to live independently within their own homes for as long as possible and how it helps us, as a country, achieve the national health and social care outcomes.

Greater investment in this area will achieve more positive outcomes for individuals and, ultimately, for communities across Scotland. Investment in terms of financial resources is always welcomed and much needed. However, as third sector organisations operating in Scotland we already have the ability to come together to share our skills and experiences and to support our communities take control of their own destiny. Are we putting this to best use?
Significant improvements have been made to the health and wellbeing of Scotland’s population. That, in the 21st century, these advances have not benefited the most marginalised in our society is our challenge.

Scotland is a wealthy country in terms of gross domestic product and levels of personal income and material wealth. It is also wealthy when considering ‘real wealth’ to be the contributions of its people and nature. Studies reveal a law of diminishing returns between financial investment and levels of health and wellbeing; increased investment realises improvements only up to a point for developing countries. Beyond this it has little or no impact on the health and wellbeing of the population. So, if economic growth and financial investment is not the answer to our aim of improving the health and wellbeing of Scotland’s citizens, what should we do?

To gain further improvements we need to shift our attention from increasing material standards and economic growth to ways of improving the psychological and social well being of our whole society. Inequality makes countries socially dysfunctional across a wide range of outcomes. Evidence gathered by epidemiologists Wilkinson and Pickett reveals that higher levels of inequality are linked to increased incidence of social problems across a range of measures. It is not just the poorest in society that benefit from greater equality; reducing inequality benefits everyone.

Most current health and social care policy promotes improvements in psychosocial well being on an individual level. Attempts to address health and social problems are made through the provision of specialised services which are generally expensive and have limited effect. Services treat or manage the symptoms experienced by ‘client groups’ rather than tackle the prevalence of the social problem. Service focused interventions attempt to resolve complex issues of human relations with interventions...
that frequently engender passivity on the part of recipients. Economist John Kay suggests that our knowledge of our complex social, commercial or natural ‘environment is generally piecemeal and imperfect, so objectives are generally best accomplished obliquely rather than directly’.

How would we build an oblique approach to health and social care policy and practice? Individual budgets and Self Directed Support offer an opportunity to approach solutions to individual human challenges obliquely by harnessing the creativity and resourcefulness of individuals, families and communities. The Asset Based Community Development approach similarly has the same potential on the condition that it results in a real transfer of power and resources from the state to individuals and communities. Failure to move power and agency from the status of, as psychologist Herb Lovett would describe, ‘power over’ people to ‘power with’ people and on to a position of mobilising ‘power within’ individuals and communities would fail to harness the most dynamic and underutilised resource in country, the citizenry of Scotland.

Embedding Human Rights and the UN Convention on the Rights of Persons with Disabilities in health and social care policy and practice would provide both a compass and an anchor by enshrining equality and fairness by character rather than by choice. Health and social care policies and practice would, as a consequence, manifest the values of our society and not be formed on the basis of a calculation of the consequences.

Focussing on the effects of inequality provides a policy handle for improving the health and well being of our whole population. To support this we need a political narrative that provides a shared vision capable of inspiring us to create a better society; one that moves the focus from economic growth and an individualistic striving for personal betterment to a vision of a more equitable, just and sociable society that is better for all.
Let me fast forward to a Scotland that has banished its decades of poverty and inequality and has a vision and practice of social policy embedded in a commitment to social justice. That vision demands that our health services and our sense of wellbeing are shaped and determined through the direct engagement of, and with, our communities at national and local levels.

Community members and groups are being supported and empowered to influence decision-making at all levels and articulate the health benefits brought to them personally and the wider community. While retaining the critical role in the delivery of essential medical services, health practitioners are working jointly with community and voluntary organisations to plan and deliver services responsive to expressed need. This is bringing radical change to the landscape of approaches to local health needs together with the resource allocation necessary to support and capitalise on a community-led approach.

Not mission impossible, but this vision is not without challenge

The economic and structural change required to eradicate poverty and reduce health inequalities can be found in political and academic analysis elsewhere.² My focus is on building healthy communities with local people who are in control of their lives and living circumstances, who are treated as equals by others, who manage things in ways that avoid stress or dependency, enjoy networks of support and mutual interest with others, have confidence and skills to engage as equal partners with service providers and who have expertise to bring creativity and inspiration to joint solutions for improving health.³

Janet Muir, Manager, Community Health Exchange (CHEX)

The last three decades in community-led health work have demonstrated important insights and produced evidence of the nature and extent to which communities’ involvement can positively influence health outcomes.

But current evidence highlights a type of postcode lottery in levels of commitment to, and understanding of, this approach, and of coherent strategic thinking. There is too much dependency on champions to advocate the case for community led health and for those advocates too often to be on the periphery of influence and decision making processes. We seem to have limited success in passing on the lessons learned from good practice and being able to scale up that practice.

This situation can be turned round with a political will and a coherent strategy that ensures community-led health plays its full part in preventing ill health as well as building local strengths that lead to healthier and more prosperous communities.

What can we do to achieve our vision? Here are my top tips for practical action at a local level that I believe will lead to lasting change:

- Invest in processes that help us gain a clear understanding of community needs and issues.
- Develop the evidence and knowledge that a community-led approach is contributing to good health and wellbeing.
- Build confidence and skills e.g. organisational, alliance building and negotiating that unleash community assets that in turn lead to a healthier community, thereby decreasing gaps in health inequalities.
- Invest in building a culture of collaboration and participation leading to sustainable change.
- Implement tried and tested, effective and inclusive methods for working with communities.
- Work with people in empowering ways, which will lead to positive change for them, their families and the wider community.
- Devise and implement processes robust enough to effectively share learning and scale up good practice.

The vision is achievable and within a timescale that is immediate rather than long-term. The above actions can help create an environment that not only prevents people becoming ill, but improves their quality of life and leads to better health outcomes for all. Working in this way with communities is only one part of the range of measures needed to tackle health inequalities, but it will be critical in turning today’s vision into tomorrow’s reality.

Can you imagine this as your future? This is a direct quote from an ENABLE Scotland member – from a mother, talking about her own child. It was given in response to a question about how she imagined the future for her son, when she was no longer able to care for him. Her son has a learning disability, and despite her advanced years, she still cares for him at home. Her fear and anxiety about what the future holds was so great that she was unable to picture a life for him that did not depend on her caring for him at home. Sadly, in modern Scotland, she is far from alone in this crippling fear of the future.

This year, 2014, is ENABLE Scotland’s 60th anniversary year. As we celebrate this milestone for our charity, we are looking back over the decades. We are reflecting on our achievements, and recognising the contributions made by thousands of our members to our successes, and to the improvements that have been made to the lives of people who have learning disabilities and their families in Scotland. But we are also looking to the future.

Because of course, this year, 2014, is also the year of the Scottish independence referendum, where Scotland’s future is in the spotlight. And so, whilst reflecting on our history, we are also talking to our members about their futures. Inevitably, these conversations are framed by the imminent referendum. What would a future independent Scotland mean for people who have learning disabilities, their families and carers? It is interesting that the contents of these conversations with our members, the issues and concerns they want to address, are very different from the topics of debate covered in the media.

Our members are not concerning themselves primarily with fluctuating oil revenues, currency union or public sector debt. They want to know if the health inequalities they suffer, which contribute to the fact that people who have learning disabilities die on average 20 years younger than the general population, can best
be reduced in an independent Scotland or in a Scotland that remains in the UK. They want to know how Scotland can best ensure that social care and health services are adequately resourced to meet the needs of the growing population of people who have learning disabilities. They want to know that the Scottish education system is able to provide the best possible learning experience for young people who have additional support needs, who are currently four times more likely to be excluded from school than the general school population.

And, of course, they want to know that in a wealthy Scotland, independent or not, no one needs to fear for the future so much that they hope their disabled child dies before them. They want a Scotland where everyone who has cared for a disabled child has the peace of mind and dignity that comes from knowing that plans for the future of their loved one have been put in place, and that these plans afford your loved one the opportunity to live a meaningful life as an equal, contributing citizen of Scotland.

Nothing our members aspire to for people who have learning disabilities and their carers is unreasonable – it’s really no different from what most of us would want for ourselves, or for our children. To be healthy, to live well, to do the things you want to do, to make your own choices, to have friends, to feel safe. Yet somehow, because you have a learning disability, or because you are a carer, it is much harder to achieve.

I remember another, younger, mother describing to me the battles she was having with her Local Authority about her son’s education in a mainstream school. She told me that she knew the only reason she was having these battles at all was because of the progress that had been made by previous generations, and by organisations like ENABLE Scotland. She was not fighting for the right for her son to have a formal education in the first place – this had already been achieved, in no small part thanks to the work of ENABLE Scotland’s members in years gone by. Her battle was about ensuring he experienced the best possible education, both for him, and for the generations of people who have learning disabilities who will follow.

And so, for our vision of Scotland (independent or not) to be realised, we must ensure the voices of individuals and families are strong, and are projected through voluntary organisations like ours. We must use this voice to ensure we continue the shift in thinking and practice that has been happening throughout ENABLE Scotland’s history. We have already seen people who have learning disabilities go from being ‘patients’ to ‘recipients of care’. We are in the early days of seeing them move from being ‘recipients of care’ to being genuinely ‘equal partners’. People who have learning disabilities are also now living in communities throughout Scotland, and are ‘friends’ and ‘neighbours’. ENABLE Scotland will continue to do everything we can to complete this transformation and realise a more positive future for people who have learning disabilities and their families, and by extension for Scotland to become a truly inclusive society that values all of our citizens as equals.
MacDiarmid, in rebutting the claim that Scotland is a “small” country, strongly asserts its “multiform” and “infinite” character. On the hillside where some can see “nothing but heather” he detects also, in a kaleidoscope of colour, blaeberrys, blue berries, bog-myrtle, tormentil, milkworts, sphagnum moss, sundew, butterwort, harebells, butterflies and rowans. Our imagined picture of a healthier, happier social landscape of the future is surely crammed with a similarly rich diversity.

Yet there is one type of variation, deeply rooted in our social landscape over many generations, which we must be inclined to root out. The variation in measurements of health and wellbeing between one local area and the next is so extreme as to strike at the heart of all our hopes for a more socially just, better adapted country. Often for better but frequently for worse, the quality of the lives we lead in Scotland is, more than anywhere else in Europe, highly determined by the local area in which we live. The distance between, for example, Bearsden and Drumchapel may be barely two miles, as the crow flies; yet measured in terms of economic, health and social outcomes they are as far apart as Balta and Drummore.

Consider these sobering comparisons between the least and most deprived areas in present day Scotland:

<table>
<thead>
<tr>
<th>Measure</th>
<th>Least deprived</th>
<th>Most deprived</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of income deprivation</td>
<td>3%</td>
<td>53%</td>
</tr>
<tr>
<td>Crimes per 10,000 people</td>
<td>51</td>
<td>3,180</td>
</tr>
<tr>
<td>Average school leaver attainment score</td>
<td>288</td>
<td>79</td>
</tr>
<tr>
<td>Emergency hospital admissions per 100,000 people</td>
<td>5,812</td>
<td>22,794</td>
</tr>
<tr>
<td>Emergency over age 65 hospital admissions per 100,000 people</td>
<td>8,602</td>
<td>55,769</td>
</tr>
</tbody>
</table>

Inequality of economic opportunity is tightly woven into the fabric of Scottish society, great wealth (and its attendant privileges) existing cheek by jowl with considerable want (with its inevitable consequences for life chances). As health and social care professionals, but primarily as citizens of Scotland, we need to ask ourselves why we have failed to rid our society of this level of ghettoised inequality. And whether or not we yet have the capacity to imagine a better future.

For it’s not that we haven’t known this stuff for a long time - as fledging social workers in the mid-seventies we all read “Born To Fail”. And it’s not that we haven’t had the conceptual tools to assist our understanding – though through rhetorical abuse and piecemeal application notions of “prevention”, “asset-based approaches”, “building community capacity”, “community regeneration” etc., etc., are in danger of becoming nothing more than hackneyed buzz words. For some time though, Colin Mair and others have been urging upon us in the strongest possible terms the importance of tackling the social and health problems facing Scotland at the very local level: the level of the district, community or several thousand neighbourhoods they have defined.

So let’s have the courage to imagine the future, and to imagine Scotland healthy!

What might it take to get there? A strategic political will, certainly; but also a smarter approach to its application:

• being truly committed to working intensively at the level of the local neighbourhood
• truly transferring power and control to the people living in the neighbourhood
• understanding the local neighbourhood as an organic whole with interdependent aspects and dimensions – and therefore not focusing on a series of separate “problems” to be “fixed” or “tackled”, nor commissioning national organisations to work remotely with specific, segmented groups of stigmatised or disadvantaged people

• planning the future on the basis of the above understanding.

And what might it look like? It’s a future where each individual neighbourhood is:

• economically strong, with well-paid jobs widely available
• socially diverse
• culturally vibrant (celebrating its “multiform”, “infinite” nature)
• mutually concerned with the health and wellbeing of its members, underpinned by networks of local people leading local organisations working to the benefit of the neighbourhood as a whole
• inclusive of those previously threatened with isolation on account of perceived difference
• achieving the full range of positive economic, social and health outcomes currently denied to so many.

Of course, on the evidence of the past fifty years or more this “starry talk” may be nothing more than “a wheen o’ blethers”\(^1\). Not that we lack the know-how, but we may lack the will. Let’s harness the power of the imagination to the necessary hard work, optimism and knowledge, to continue to fashion and refine that vision of the future without which many people will continue to perish.

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8“Born To Fail”, Peter Wedge and Hilary Prosser, National Children’s Bureau (1973)
9Colin Mair, Improvement Service www.improvementservice.org.uk
My vision of how we can shape a future in which people live well and communities thrive is based on what needs to change much beyond health and social care. We know that so much governs our health and wellbeing beyond what we traditionally thought of as ‘services’. We know that the wider wellbeing environment matters; the food supply, how much and where we consume alcohol, our opportunities to walk rather than sit in a car. But we also know too that there are things much deeper in how our society has developed that need attention. And to suggest so is not an argument for social engineering – rather for a flourishing of the assets within people and within communities. At its best this is what the third sector can bring to the challenge of helping us all to live well.

Chief amongst these deep seated challenges is something Jimmy Reid highlighted over 40 years ago in his rectorial address to Glasgow University namely ‘alienation’ (it’s worth looking up if you don’t know it). He referred to a lack of control of destiny, a lack of opportunity, an exclusion from decision making. He saw a society of passive recipients, of fates decided elsewhere. Now great strides forward have been made since then. We don’t defer as much to authority. We are probably more health-aware if not all of us healthier. However where alienation matters is in its confluence with a massive concentration of inequalities amongst the poorest in Scotland and in my vision of Scotland this would no longer be the case.

That would require some pretty fundamental shifts in mind-set. In another 40 years’ time I want communities alongside the state and the third sector to be able to ‘co-design’ the services around them and for each to be involved: not two of those to be done to by the other. This is the opposite to centrally lead technocratic design. It’s much more bottom up. At the same time though it isn’t instead of nationally lead action. In fact paradoxically we might need more. The critical point is an unfashionable and seldom
heard word: subsidiarity. Our obesogenic food system for example will require European or even international action. Centrally lead direction of how our food system works locally is not the answer, though nor is absence of direction such that market forces can squeeze out ‘health’. In fact a greater citizen role locally with some teeth behind it nationally could improve a whole series of outcomes.

When we think about it; why wouldn’t we want citizens at the centre? Self-management recognises this, self-directed support attempts to recognise this, a better quality of community engagement could recognise this. In other words we get it (or at least some of us do) – we often allude to it but we never quite make it happen at such a scale as to reduce the alienation Jimmy Reid talked about 40 years ago. Necessity may be the mother of invention in the next 40 years though. The apocryphal ‘graph of doom’ tells us what happens to demand and public money over the next few years (I needn’t remind you) but there is another way: co-produced, person centred, flexible – with me, not to me, but, with the backup of a state willing to tackle the factors beyond me, my local community or my council. Change, of course, is hard. Change in culture is even harder but we’re ready in the third sector. In fact our network – the Third Sector Interfaces in Scotland – ally with the third sector locally to promote and develop many of these approaches now. So, we’re up for building that future – are our politicians?
Shaping our future starts with the present. Changes made now will reap benefits for our future selves but must be rooted in the reality of people’s lives. It is good to have an aim; this how we inspire ourselves and others. But conjuring up the equivalent of jetpacks – oft-promised gadgets yet to be delivered – for our services and communities isn’t in my mind when I think of my vision for the future. I am thinking about what can be done today, with our current assets and resources, to unlock multiple potential futures.

Working in diabetes, I see those futures playing out. Health is not just about the NHS and diabetes is not just a medical concern but a social, economic and environmental one. Diabetes, Type 1 and Type 2, is an indicator for deprivation, for inequality, for the impact that wider approaches to food, transport, access to open spaces and well-designed living spaces can have on the health of a nation. It exemplifies why tackling preventable issues is an exercise in problem management, doing the best you can to delay avoidable yet inevitable negative outcomes – rather than tackling upstream issues proactively, with creativity and vigour, to ensure that the experience of a decent quality of life in Scotland is an everyday and almost banal occurrence.

Now and in the future, the integration, development and redesign of services is not just desirable, it is necessary if we are to have a healthy, happy nation.

An area we can work on now is not ‘how others see us’ but building the confidence of each other and communities to own the idea that we deserve and can create a better future and can visualise ourselves within it. How much do we believe that we should have access to healthy, affordable food, to cycle and walk to work and school freely and safely; that housing should be safe, secure and designed to support wellbeing?

The phrase ‘What’s for you, won’t go by you’ to me epitomises some of these issues. On
the one hand there is comfort in thinking that if something doesn’t go well or have a good outcome that this is somehow down to the fates. On the other, it is a passive approach that implies there are good things that will pass you by, things not meant for the likes of us. Right now, many things go by us and our communities – when do we develop the confidence to stand up, join up, to catch these opportunities and use them?

A young woman with Type 1 made the point to me recently that she did not disengage from her diabetes – because if she did she would be dead within a matter of weeks – she disengages from services. This is an important distinction because we often talk about disengagement across the gamut of health and social care services. There is the phenomenon of passivity amongst service users who are ‘done to’. People do not disengage from their lives – they are living them right now. But have we supported and enabled communities and each other to unlock all of the assets available? Do we help or hinder? Do public services welcome and encourage dialogue and true joint working between those who deliver and those who use? The third sector understands engagement and co-production right now and we don’t need to wait 30 years to use these skills. Too often the complexity of services, of infrastructure, of our own entrenched learning about ‘how things should be’ gets in the way.

The future I imagine is a place where we look back and wonder at why it took us so long, and why we were so timid, at recognising our own abilities and assets to change our world.
I am by inclination an optimist; my glass is usually at least half-full. Often I rebut those despondent that change is possible by urging them to think in terms of decades. Sixty years ago polio was still familiar in the UK. Thirty years ago people with learning disabilities or long-term mental health challenges lived in long-stay institutions; older people were hidden on isolated geriatric wards; dementia was barely recognised. Even I, however, was taken aback when I returned to Scotland in 2009 after four years south of the Border. In the years before leaving, Shifting the Balance of Care had been high on the agenda; by the time I returned the headline had become Reshaping Care for Older People – but the essential agenda was the same – and even I despaired...

Futures thinking seems to be in favour at the moment. At the time of writing #anticipating 2025 is in progress, talking of ‘nanotechnology’, ‘benevolent memes’ and ‘love and sex with robots’ (sic). But let me introduce you to Alex Chisholm (http://content.iriss.org.uk/itf/). We created an animation of Alex’s life in 2025 to introduce people to three reports we had published on specific aspects of the future: citizenship, the workforce, and enabling technology. Some have felt that although technological developments allow Alex to communicate readily with family elsewhere and prompt him, for example, to take medication and to cook safely, Alex remains lonely.

Scottish Association of Social Workers (SASW) commented: ‘what many came away with was a sad picture of a man very alone that lingered for a long time’.

We could argue on the detail but the underlying principle is critical. The future, whenever it is, is not about the latest gizmo, about stretching digital possibilities to ever new boundaries, about cryogenics. It is about the capacity of the human spirit to embrace those around them, to care about their lives,
their hopes and their dreams, and to offer those moments of contact, dignity and respect from which we all gain nurture. This is not to deny the value of the scientific and digital advance; it is to afford it its appropriate role as a mere sideshow, an adjunct to the real challenge of a society built on and driven by social justice.

By 2025 I will be a decade into that phase of life labelled ‘the third age’. I hope of course that I will be amongst the majority of older people who remain fit and active, doing all the things they were too busy to do when working. I will certainly, whatever my condition, be protesting with weary repetition on every occasion when I am referred to as ‘the elderly’ or ‘the vulnerable’ or people assume what I may wish to do or take decisions on my behalf. If I do require elements of support, I will of course expect to choose and manage them through self-directed support – and health and social care will of course be integrated. It had better be working well: I will be in Highland and they claim to be ahead of the game...
Dementia has been written about since antiquity. There are few conditions that can trace the development of stereotype and stigma right back to Aristotle and Plato, who both described dementia and labelled it as a disease you can do nothing about.

The stigma of dementia has been embedded like a fossil in the rocks of our society for thousands of years. It is only through the ongoing efforts of the many people that have devoted their lives to campaigning for the rights of people with dementia and their families that we have chipped through this rock and now see its true shape and so hold in our hands a clear understanding of the past; and the power to change the future.

So what might that future look like? In my mind this should be governed by the simplest concept: form should always follow function. We must know what it is we set out to achieve before we build a structure to deliver it. Too often we start in the middle, and we move, merge and create structures that accommodate rather than deliver.

The future of our support system, our community engagement and our individual commitments to people with dementia and their families, carers and partners must be built on the right principles, and it is these principles that we should build our support structures around. Belief in a basic right to citizenship, to equality, to the power to choose and to control must inform the fundamental transformation of our system.

Henry Simmons, Chief Executive, Alzheimer Scotland
For people with dementia we must ensure that we do this as soon as possible. This transformation has started in Scotland; we are the first country in the world to place human rights principles at the heart of our system and our national dementia strategy. The way we provide post diagnostic support, for example, is entirely founded on these principles. The clarity of this model will mean that the form of the structure we build around this function will ensure a better outcome for people diagnosed with dementia, an outcome which will guarantee that their choices, their hopes, their wishes and their strengths are what we build their support around as they journey through the illness.

It has taken a long time for our policy leaders to remember that people and communities have many strengths and indeed have coped, evolved and developed through many challenges without the need for professional engagement. We now know that we need only ask. We now understand that our health and social care system is but a small part in people’s lives and that we can only add value by contributing rather than controlling. This shift will ensure that we see the true value of our total combined resources and skills. Alongside this if we continue the drive to engage our youth, to work with our political leaders, to develop more dementia friendly communities and to ensure a meaningful commitment to increase the level of investment we make in research, we might equip the next generation to truly release that fossil and consign the myth and stigma around dementia forever to the annals of history.

This is how we can offer hope to every person who develops dementia in the future and to their families, partners and carers that they will not be left out of society and excluded, but included and welcomed; that they will be treated as equal citizens, and given the best possible care, support and treatment to ensure that they live well with dementia. In this future Scotland will have a personalised system of health and social care that is in itself the form for truly delivering the principles of human rights.
Cancer used to be something people died from. Now thanks to better treatments, the numbers of people surviving cancer is increasing.

Coupled with the increase in the number of people being diagnosed with cancer – in large part down to the aging population – there are more people than ever living with or beyond a diagnosis of cancer. In fact our research estimates there are around 190,000 people in Scotland who have been diagnosed with cancer and this is expected to rise to around 340,000 by 2030.

This creates a huge set of challenges for the NHS, charities and local authorities, particularly social care services. We know the current system of care doesn’t meet the needs of people who have had a diagnosis of cancer, with many people unsure where to turn for emotional support, financial advice, practical help or even advice on coping with the side effects of treatment.

That’s why we are working the Scottish Government, local authorities, the NHS and other agencies, to create a better system - one that gives people who have been diagnosed with cancer support and care based on their individual needs for as long as they need it - not only until treatment ends.

One of our key projects is the new Improving the Cancer service in Glasgow which launched in February. This ground-breaking service will soon send every newly diagnosed cancer patient in Glasgow a letter offering a visit from a dedicated one-to-one support worker.
Those who take up the offer will receive a Holistic Needs Assessment to identify the kind of help they need, from childcare and help at home, to cancer information and benefits advice.

Macmillan hope the project, being delivered in partnership with Glasgow City Council, NHS Greater Glasgow & Clyde, Cordia and Glasgow Life, will transform the experience of people affected by cancer in Glasgow.

Glasgow is the first place in the UK where social care services are working with the NHS to make sure cancer patients can access all the help they need, and Macmillan believe the pioneering approach could become a model for cancer support across the UK.

This project follows on from a £5m programme Macmillan is funding with the Scottish Government, which aims to transform cancer after treatment ends. There are two main strands to our Transforming Care After Treatment work.

Firstly we want to make sure a wide range of support, from practical help to financial advice, is available to those recovering from cancer until they no longer need it, even if that is months or years after treatment ends. Secondly we must move away from the one-size fits all system of cancer follow-up care to more individually tailored aftercare.

Some people affected by cancer will require consultant led follow up, however, a growing proportion can be prepared and supported to self manage, with remote monitoring and timely re-access to the system initiated either by themselves or professionals.

We’re working with the NHS to move towards this kind of aftercare for people with cancer and while we are still at the very early stages of this project, we are seeing encouraging progress in less than one year since its launch.

With the number of people living with a diagnosis of cancer in Scotland expected to increase rapidly over the next 20-years, Macmillan’s aim is quite simple: we want to transform cancer care in Scotland. There is still a lot of work to do but we believe we are on the right path to make sure that the Scotland of the future will be a place where no one needs to face cancer alone.
In Scotland we are fortunate to have health and social care systems which are geared towards supporting people to live long, healthy lives, cure illnesses and prevent people from dying prematurely.

However, no matter how skilled our staff, how safe our hospitals, or how clever our medicines, we will never be able to eradicate death. In fact, the number of people dying is expected to go up by 17% in the next 20 years.

Most of us will die when we’re over the age of 75, and with more than one long term health condition. One in three of us will die of cancer. One in three will die from organ failure. And one in three of us will die with dementia or because we get old, frail and things stop working.

Yet death and dying is no place for fatalism. We cannot stop death from happening, but there are lots of things we can do to improve the way people approach their deaths.

Conventional approaches to improving people’s experience of decline and death have focused on improving the health and social care infrastructure - training staff, providing guidance, and introducing systems and processes to improve care. All of this will remain just as important over the coming decades.

However, our experiences of death, dying and bereavement are only partially determined in our interaction with traditional formal services. The culture we live in and the support we receive from our family, friends, employers, education system, governing bodies and wider society have a huge impact on how we live, decline and die.

Many problems are caused because as a society we struggle to be open about death, dying and bereavement. 60% of Scots die without making a will, leaving potential for family conflict and financial and legal
complications at an already distressing time. People who are dying or bereaved can experience isolation because family, friends and communities are afraid of saying the wrong thing.

If health care professionals and the public don’t acknowledge the possibility of dying it makes it hard to discuss a person’s preferences for care, reducing their chances of receiving the kind of care they would choose. People nearing the end of life may undergo futile and aggressive medical interventions they wouldn’t wish for, at the expense of quality of life. This is harm that could be avoided.

In recent years there has been a welcome national focus on reducing avoidable mortality in Scotland’s hospitals. However, most deaths are not the result of avoidable mistakes or poor care. Rather they are the consequence of aging or irreversible natural disease processes. Good end of life care is core business for hospitals: 1 in 3 beds are occupied by people in their last year of life and nearly 1 in 10 people in hospital will die during their current admission.

Many significant pieces of policy have been produced with little or no acknowledgment of irreversible decline and death as a significant issue that health and social care systems must be equipped to deal with. Without explicit and open engagement at policy level about decline, end of life and death, improvements in care for people at the end of life are unlikely to be made.

Our vision is for a Scotland where communities and individuals are able to help each other through the hard times which can come with decline, dying, death and bereavement. People with advanced disease should experience safe, effective, person-centred care from health and social care services which understand that they can continue to make a significant difference to a person’s wellbeing even in the last months, weeks, days and hours of that person’s life.

This vision can only be achieved if as a society we recognise that decline, dying, death and bereavement are not issues which fall solely or even mainly within the domain of health and social care. They are fundamental parts of everyone’s life experience.
My experience is that communication within the NHS has been a problem. I have found that departments do not always communicate efficiently, consequently leaving me confused and my treatment delayed. When I have spoken to friends and colleagues I have found they have had similar experiences and many people believe that the service you get tends to be a postcode lottery. The media have reported numerous horror stories about poor treatment of people due to human error. This is certainly not what any of us want to experience.

What if anything can we do to improve communication over the next twenty years? I would like to think that the Scottish Government would put a big emphasis on communication and being coherent. This clearly needs to be led from the very top and filtered down to all departments. I would hope that there would be some form of framework to tie the NHS in with different organisations for the benefit of people who use health and social care support and services.

This could involve keeping treatments as local as possible, rather than causing people to travel for miles; a main computer framework for all that could identify the path the person would have to take and a structure not only for the person but for whoever is giving the treatment, making sure that their experiences are listened to and they...
are receiving the appropriate treatment. This framework not only needs to work for the person’s treatment, but for the use of transport to and from all departments.

We should also enlarge the network of work being done with third sector organisations at present. This should include both the larger more well-known organisations and smaller organisations, who both work hard in their particular fields with much of the work they undertake done by volunteers. This would be of great benefit for people, particularly those, for example, who have just been diagnosed and who can be signposted straight to the particular organisation required.

Forward thinking, communication, treatment/experience, cost savings in the long term must drive a framework such as this.

In summing up, I feel that the rule of thumb is communication. This has to be the same with any communication to the person, making sure that it is clear and concise.
Patients and carers with a formal role in service development

1. There is more than patient ‘involvement’ in this vision – there is legal enshrinement of roles and rights in a new care compact – for practical economic reasons, not just democratic ones.

From the most personal perspective, as a carer for someone with Asperger’s, the lack of carer involvement in the design of care until recently, means that many people with this condition were not diagnosed until late adulthood, and services were few and fragmented when they are. The clinical and economic consequences of this approach benefit no-one.

As a researcher, looking at telehealth services in many chronic conditions, patients and carers are clearly an under-used resource that can be leveraged to cut the cost and risk in designing and delivering services that work in practice. (Remember NHS Connect?)

A key recommendation in the BMA’s most recent report on H&SC integration in Scotland is that Health Boards demonstrate the involvement of doctors as part of the accountability process. By 2020, I hope that patients are also as indispensable to the decision-making process.

Customer feedback is used to shape services in business organisations – from TESCO to Amazon. The current consultation for carers points in this direction but like H&SC legislation, it would have to be legally required in this vision. The cost of failed digital services such as NHS Connect cannot be recouped, but future costs can be avoided.

User-led research and service development communities

2. Patients, and organisations representing patients benefit more directly from the information, monitoring and lifestyle data they generate, and often carry out research around their members’ needs.

As home monitoring and lifestyle data becomes more important for research, companies are jostling to access patient provided sensor and lifestyle data for research. Rather than being guinea pigs for research, patient groups and digital communities would have a lead role in collating this data, shaping and carrying out research as well as service development that meets the need of their members. Research funding would also be more accessible to patient groups, and Care organisations who represent them. The data they hold would give them a greater role in shaping and carrying out research and service development that really meets their needs.

Personal and community managed data stores

3. Health data would be ‘pushed’ on request, rather than ‘pulled’, and ownership, curation and security would remain with individuals and communities through personal or community data stores.

Patient groups would increasingly curate and manage access to their own health data, together with increasing use of personal information management systems such as Mydex or the Citizen’s Account portal. Personal and community managed health information not only provides a valuable resource, it makes patient groups attractive partners in research and service development consortia. There is also evidence that local data management leads to better data quality and data governance. By 2020, sucking data from GP-held records into a centralised database (such as Care.Data) will be increasingly associated with poor data quality and poor data security.

Integrating health information and services around patients/carers

4. NHS patients will have access to information and services like PatientView for all their conditions, sharing their current information, test results, medication with a distributed healthcare team in hospital & at home.

An integrated patient pathway across H&SC will depend on patients (and carers) being able to access, share and communicate this across departments and sectors.

Research here and in Europe increasingly highlights the clinical, social and economic benefits of putting patients at the centre of healthcare information and service development or co-production.

Council service providers who’ve tried putting citizens at the centre of service provision (through personal data stores), also found that this was cheaper than maintaining multiple incompatible databases for multiple departments.

Learning from other regions

5. By 2020, I hope we will be learning from other sectors and countries, and will have developed shared standards for mobile applications and Open Source software applications, so we are not excluded from these huge emerging markets.

Developing countries have leveraged the social infrastructure and the mobile service infrastructure to do much more for much less. My colleagues in Latin America use their students to develop Open Source applications rather than commercial ones, and do much more collaborative action research in the field with communities to identify needs and support implementation. By 2020 I hope we are sharing their experiences, sharing standards and finding synergies with other regions, rather than re-inventing the wheel!

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Research Community Partnerships
15 www.sustains-eu.org 16 http://www.youtube.com/watch?v=2wJ5_lF7ss8
Person centred care is never more important than when someone is approaching the end of their life. Terminally ill patients and their carers often need to access care packages that need health, social care, housing and other services to support not only their physical needs but also emotional, social and spiritual requirements.

Such a whole person approach requires key partners to co-produce services together with the patients and their carers. All need to be involved in service design, planning and local ownership from the very beginning. The third sector plays a vital role and can bring innovation and cultural change as well as empower the people they support and advocate for to have a crucial role in the development of services.

With the passing of the Public Bodies Bill we need to see the health and social care integration agenda accelerate with real change being achieved for patients and carers.

Marie Curie has already seen some success with integration through programmes such as Reshaping Care for Older People, which is designed to improve health and social services for people aged 65 or over. For example, Marie Curie’s Glasgow Fast Track Discharge Service has supported the discharge of over 400 palliative care patients, resulting in avoidance of 105 re-admissions into hospital. This has led to many patients being able to return home to be cared for, where they would like to be. This service is delivered in partnership with community nursing teams, an acute hospital team, an independent sector provider, the local authority and the Marie Curie Hospice, Glasgow.

However, much more still needs to be done...
across Scotland to achieve the change that is required. A recent Audit Scotland report on the Reshaping Care for Older People programme found that progress has been slow, and improvements need to be made. Integrated services must be able to demonstrate evidence of success in achieving outcomes and not just at bringing organisations together.

There are other challenges that the integration of health and social care services will need to address if we are to deliver person centred care for all. Scotland’s population is ageing and more and more people will be living longer with complex and multiple conditions and terminal illnesses. The number of people dying each year will rise substantially and this will present a significant challenge by increasing the demand on services at the end of life.

This, combined with an economic and political environment, will see less public finances available to fund services. There will need to be on-going innovation in service design and delivery driven by all partners as well as flexibility in order to ensure that services truly reflect local need.

Statutory partners must recognise the value and expertise of the third sector in designing and developing services, as well as have a wider understanding of what third sector resources are available in their areas. This must include greater community engagement and mapping to ensure that all organisations that can contribute are involved in co-designing services. Third sector organisations must also be willing and prepared to work in partnership with other third sector organisations.

There is information that terminally ill patients are entitled to know; when medical professionals expect death is coming, what they can expect from their disease and how it will progress. They should receive pain relief, they should have as much choice and control as possible over their care and their place of care, they should be able to access spiritual and emotional support, be supported to develop advance directives about their care if their condition deteriorates and they can no longer make decisions. Above all they should be entitled to dignity and a chance to say goodbye to their loved ones. This is the person centred approach to the end of life that we would hope that all people in Scotland would be able to have.
Health and social care will chart new territory over the coming decades. Our population will live longer (rebalancing the social contract between the generations), demand for health services will greatly increase, public finance will remain tight, and technology will transform daily living.

For disabled people, those living with long term conditions and unpaid carers, these changes will bring unprecedented opportunities and challenges. As a nation, we will either succeed or struggle in managing change.

If we struggle, then the number of people facing significant sight loss could double by 2030, outpatient attendance at eye clinics will grow well beyond the current 18% of all hospital visits, putting even more pressure on public services and leading to potential isolation for blind and partially sighted people.

Our potential to succeed will rest on our ability and commitment in the short to medium term to:

- Embed prevention strategies within our care plans, budgets and structures.
- Embrace sustainable self-care.
- Build on global practice and innovation.
- Harness technology, both at an individual and organisational level.

We need to rethink and restructure existing models of care and support around the above elements.

But the seeds of success are already evident. Scotland already has a world class eye-care integration programme that enables high resolution digital images taken in local high street optometrists to be diagnosed remotely in hospital eye clinics. This cuts referral and waiting times and increases access to sight-saving treatments. Just as significantly, it is helping to shape new care pathways and is building an invaluable database for future planning and research.
Today, 50 per cent of all sight loss in Scotland is preventable. By 2030 medical research will have substantially increased the chance of preventing avoidable sight loss and extended the early identification of health conditions such as diabetes. Whether or not we maximise that potential will depend on how effectively we screen and support self-care at a local level.

Techshare Europe, RNIB Scotland’s technology conference held in Glasgow, brings together the private, public and third sector with service users to explore new technological developments in the fields of travel, work, leisure and health, and provides a focus on how these can be utilised by individuals.

Through our work with companies and organisations across the world, a normal mobile phone can now be used as a low-vision magnifier, read bar-codes on shopping items, and help users navigate our villages and cities. From cars that can drive themselves to glasses with digital cameras, from accessible transport systems to self-monitoring health systems, it is now possible to solve many age-old challenges of sight loss and enhance independence.

If you are blind or partially sighted it doesn’t matter where the technology or the clinical solutions are developed. Low cost pathways and tools, designed out of necessity for the developing world, have the potential to challenge established models of care.

For those at risk of or living with sight loss, the opportunities are enormous. But the rate of technological innovation is increasing exponentially. Consequently there is a significant risk that those with most need will be left behind. Our challenge is to maximise and bend global opportunities towards local solutions.
“Recovery is not only possible for you - it’s inevitable!” These were some of the first words that Lee’s facilitator had said when they met in 2025. At the time it was a hard idea to accept. Things had become so bad – terrifying thoughts racing, self-loathing, convinced people were plotting against him and worst of all a desperate desire to end it all and to stop being such a burden on everyone. So yes hard to accept but the words had somehow found a home in some deep recess of Lee’s exhausted mind where they incubated and slowly re-emerged when it felt like there might just be some grain of truth in them.

Like everyone these days Lee had heard all the stuff about mental health being a continuum - he’d also heard about a time when people used to be categorised and labelled for the convenience of services and forced to have treatments that they didn’t necessarily want. All that was gone and these days everyone was involved in community support systems, no more hospitals. For Lee, like so many other people in his area the community wellness centre had become really important. Everyone was involved one way or another with the centre, whether it be going to the café, using the library, running groups or using the community gardens. There really was something for everyone from the people on their lunch break to the toddlers group. What had made the biggest difference was when the Government had decided to start measuring wellness instead of wealth to check progress. It had all kind of clicked into place after that and now that mental health was seen as everyone’s business there was none of the old stigma that Lee had read about. It used to be all about them and us, about separating...
people out and finding difference, now it was all about us as a community looking to stay well.

At first Lee had felt pretty uneasy about the approach of the facilitators at the centre. It felt like he was having to do all the work and to come up with all the suggestions at a time when he least wanted to. It felt risky as well at first and it had been really weird to focus so much on his strengths. ‘Start with what’s strong – not what’s wrong’ was the group motto, and once Lee got used to it he started to really see how we are hard wired to do the opposite and the power in some reverse engineering!

So it was Tuesday and time to logon for some more guided wellness with the others – sometimes being online suited Lee better because it minimised disruption with his Uni work. The Facilitator was right, recovery was inevitable for Lee but that didn’t mean it was easy or that it was over. There were still times when things became unbearable and that nagging doubt and feeling of worthlessness came back but he could see his progress and felt a real hope for the future. If he needed it he knew that he could get a little extra support day or night.

Lee had to admit that he’d come a long way in a short space of time. He’d never wanted to give up Uni and he hadn’t had to – graduation soon and then goodness knows what. Maybe he’d get into facilitation himself – it was such a great job but really hard to break into. He knew at least that his lived experience would give him an extra chance of being selected. The people in the group had complemented him on his relational skills but he wasn’t so sure. That’s what it was all about these days – relational skills – ‘the evidence based approach’ or so they said.
Scotland – small country, big ideas
Imagining the future...

The brave new world; a primary care perspective

I’m a GP in Montrose, Tayside. For the past two years I’ve been working 2 days a week with Scottish Government looking at how healthcare can enable people to have sufficient confidence, knowledge and skills to cope with the demands and expectations that living with long term health problems places on them.

We live in an age of growing medical, social and cultural complexity which is placing unsustainable demands and expectations, not just on our patients but on us healthcare professionals and the system we work in. A colleague I met recently summed it up by saying: “We are all just feeling scunnered”

Our endless data gathering, focus on single diseases, guidelines elevated to paramount importance by financial necessity is driving, what Richard Lehman describes as, “maximally disruptive medicine” dominated by polypharmacy, monitoring, medical complexity, and unacknowledged iatrogenesis. It dis-enables our patients and promotes passive dependency that we can’t sustain.

To parallel healthcare with the energy crisis, we need to look for more sustainable and renewable resources. What if people and communities could be that resource? The Health Foundation have collected a huge number of resources showing that enabling self management approaches, where people and communities are supported in becoming the lead agent in

Dr Graham Kramer, National Clinical Lead for Self Management and Health Literacy
their healthcare and recognised as resourceful, both medical and personal outcomes improve; health service utilisation; unscheduled care; costs, waste etc all improve. It requires a transformation in the relationship between people and their professionals. It’s a different way of doing business and requires a transformation of the current healthcare model. We can’t keep adding new things on to the old one and expect it to work.

As GPs we are often very good at seeing what’s wrong but often don’t have a shared consensus on what to do about it nor much opportunity to get our opinions heard. As a result piecemeal ideas and policies get piled on, usually to solve problems that lie upstream in the healthcare system. There’s never been a clear strategic vision as to what a new model of primary care and in particular General Practice should look like. Without a clear idea of where we need to get to, it becomes difficult for anyone to change and do anything different.

That’s why I’m excited about new, but tried and tested, models of primary care that are emerging such as NUKA and House of Care. They give us a clear idea of what transformation would look like and what we need to have and need to do. Having a clear vision makes leadership happen, makes it easier to argue for resources and the true level of both initial investment, and subsequent savings, that transformation involves.

The House of Care approach has emerged from a series of pilots in England that looked at improving diabetes care. Tower Hamlets in London, with its multi-ethnic population, had the worse diabetes outcomes and patient engagement in England. The practices in the area collaborated with each other and their patients. They started sending patients their results, in clear explanatory formats, ahead of a “care planning” conversation with their GP or Practice nurse. Patients were encouraged to identify and set their own goals, and practitioners values were challenged to ease back on imposing their own values and usual medical solutions. The population began to identify their own individual and community solutions, peer support, cooking groups etc which the Health Trusts supported. Patient and practitioner engagement and satisfaction has grown, and over 3-4 years. Tower Hamlets now has the best diabetes outcomes in England. By focussing on personal outcomes, medical outcomes improved. It’s an approach that addresses health inequalities, caters for multimorbidity and true health and social integration.

We have great examples of activity that support this type of approach in Scotland, community facing activities that you might not have heard of such as The ALISS project and a pilot of Links workers connecting people with sources of local community support. It is somewhat piecemeal and the challenge is integrating it all into front line practice.

I’m confident these approaches will translate to our own contexts in Scotland and I commend you to look in detail at these models yourself.. For me they provide a much more hopeful picture of primary care and a picture I intuitively feel will make all of us, healthcare workers and people, less scunnered! When you really understand these models it begins to explain why our job is currently such a struggle. Change won’t happen without hard work over time. We need to look at how we can be freed up to champion and effect change against the backdrop of our busy jobs... but to do nothing will be even harder and, put simply, isn’t an option.
It is clear that we are entering an exciting new era in health and social care in Scotland. Let’s focus, in particular, on relationships between people who receive care and the people who provide care. People who, in the past, may have been regarded as passive recipients of treatment and support are now increasingly being recognised as equal partners in the process of care. There is growing awareness that what patients, carers and service users think about what happens to them really matters. Every day, more and more people want to step up to the challenge of taking part in the decision-making that affects them, and put their shoulder to the wheel of continual service improvement.

It sounds easy enough to make that happen right now! But experience shows that it’s not. People who have traditionally ‘had things done to them’ have to trust that what they say will be heard, and that speaking up about what needs to change won’t compromise them and will have impact; similarly, people delivering health and care have to cede some power and control, and demonstrate that they care enough to really listen - and then act upon what they hear, for the benefit of all.

It’s not rocket science, is it? No, but we’re not there yet! What will be the catalysts in achieving these new relationships, more equal partnerships between recipients and providers of care? There are many but here are two ...

Technology. Throughout the networked world in which we live, we are witnessing hierarchies of power and control across society diminishing, e.g. the Arab Spring, Martha’s meals.

It’s easier, faster and cheaper for each and every one of us to find “people (patients) like us”. Our current digital capabilities enable us to develop peer to peer connections with someone else experiencing similar conditions and care in the next street, the next town, at the other end of the country or the other side of the world. These capabilities enable us to learn from each other and to make our voice heard: the internet democratises voice and is a great leveller. And isn’t our use of technology to connect and communicate only going to increase, not for technology’s sake but for ours? Whether we subscribe to the
view or not, the providers in health and care have been in control, but that’s changing. Health and care has a great opportunity to use technology to harness the insight of people who have the most to gain (and lose) from improving health and care services – the people on the receiving end. Imagine not having to have all the power and all the answers – how liberating!

Openness and transparency. These words are becoming more prominent across health and care especially in the wake of the Christie Commission report on public services in Scotland, the inquiry into the failures at Mid-Staffordshire NHS Foundation Trust and a number of high profile issues around the provision of care to vulnerable people across the country. The public increasingly expect and demand no less. In fact, it feels like we are approaching “zero tolerance” towards anything other than tangible openness and transparency across public services.

A recent exchange on Patient Opinion illustrates just how openness and transparency is being driven by the citizen. The citizen calling themselves “frustrated but a fan” is suggesting and seeking change (with ideas!): technology enabling a voice thwarted by a more traditional means of giving feedback (the telephone) and by staff who are, perhaps not intentionally, driven by the need to maintain control and the comfortable status quo than openness and transparency.¹⁷

It’s not easy because it’s about changing the way we relate to each other: it’s about changing culture. Shifting deeply embedded cultures is never easy, a bit like pushing a large load up a steep hill, but here in Scotland, despite all the hills, we are showing that it can happen!

Background info:

The website Patient Opinion (and its sister-site Care Opinion, for users of social care services) is proving to be a powerful vehicle for making sure the patient voice is heard.

Patient Opinion – an independent and not-for-profit enterprise – allows people to share their observations and suggestions or complaints anonymously. Once these have been moderated to ensure that there are no breaches of confidence or unfair comment, they are posted on our website for all to see. 50% of the postings are positive – people wanting to say ‘thanks’ – but the other 50% carries powerful indications of where things could be better. That might mean improving the signs in a hospital corridor, or streamlining an appointments system, but it might also involve identifying uncaring behaviour by a member of staff that needs to be addressed.

The Scottish Government is supporting the use of Patient Opinion, and encouraging participation.

¹⁷Check out the full story here: https://www.patientopinion.org.uk/opinions/152683
Scotland – small country, big ideas
Imagining the future...

About the ALLIANCE

The ALLIANCE vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. It brings together over 600 members, including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals.
Scotland – small country, big ideas

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Imagining the future...

Views from members of the Health and Social Care Alliance Scotland