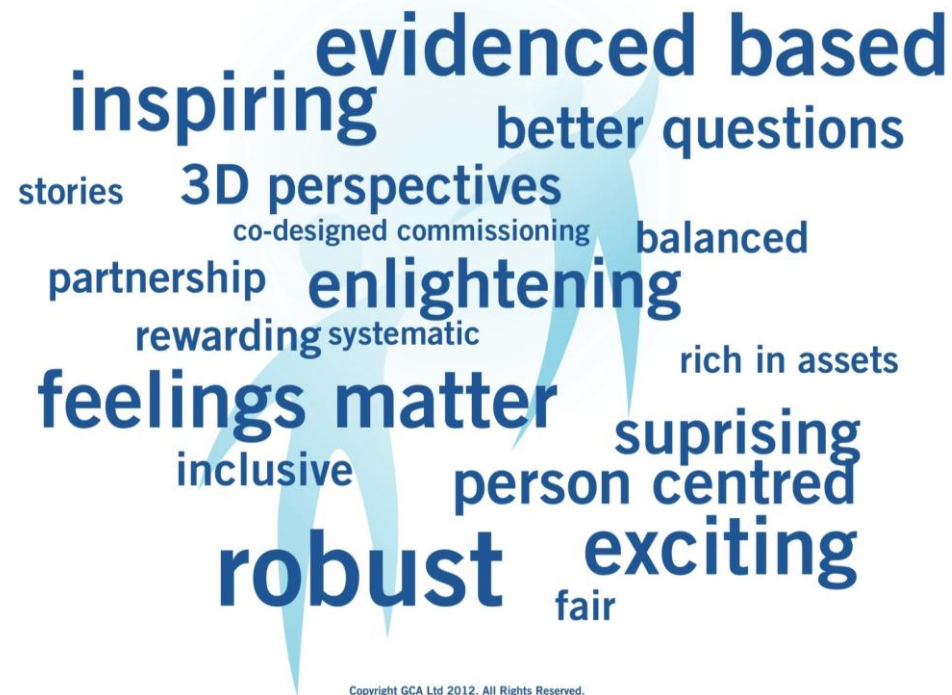




Analysis of North Lincolnshire ELC™ Co Design Programme: keeping well and living an independent life



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Contents

Executive summary	3
Background	15
Methodology	10
Experiences of keeping well	22
What matters most	30
Existing insights from other work	38
Shared vision of great support for keeping well	52
Analysis and ideas for commissioners and providers	62
Person centred outcomes	78
Index of appendices 1- 13	82

Executive Summary

People told us the essence of keeping well is quite simple:

“To keep well, I need to be able to live as independently as possible so I feel in control and can pursue my life purpose (which may well be caring for others), supported by a close social network of family, friends and supportive peers who share and understand my experience. I want one main trusted contact with whom I feel safe, who is linked into or within the health and care ‘system’ (not necessarily a clinician). I want that person to respect me, listen deeply and support and guide me. I want them to join up conversations between services – especially during times of crisis and rapid change in my life - so that I can concentrate on coping and keeping well; doing as much as possible to care for myself with support of my family and friends. This person also needs to understand my story and see me as a person. My mental well-being impacts on my physical wellbeing – and vice versa. Preserving my mobility is especially important because it’s about me staying in control and being independent. The NHS has to recognise and invest equally in helping me maintain both my physical and emotional well-being to keep me well. Often talking and being listened to by peer mentors and ‘buddies’ helps me with the emotional stuff - more than clinical people do.”

This work found that everyone in North Lincolnshire wants the same things to keep well; no matter how old or young they are.

People need support from services to a greater or lesser degree, depending on the stage of their life they are at; how robust their social support networks are and the degree to which they have the ‘life skills’ they need to keep well. The ‘Life skills’ skillset changes as people transition through different stages of their life e.g. becoming a first time parent, becoming a first time carer, retiring. Life skills are not only something that is learnt as a child. If the health system in North Lincolnshire were designed to deliver relationship based care experiences systematically in line with this narrative, it would maximise support for people around keeping well. This would prevent crisis and improve experience of transitions in care too.



This work is based on an aggregated analysis of people's current and desired experiences drawn from fourteen conversations with eight individual communities, namely: families with preschool children, families with school children, families with children living with disabilities, care home residents and staff, older people who live independently, people in recovery, people who use GP services, people who work in public services (Scunthorpe General Hospital and North Lincolnshire Council). The detailed analyses of these community conversations are reproduced in APPENDICES FOUR TO ELEVEN. It also draws on ideas generated at the community led PATH Planning Event (APPENDIX TWELVE).

This analysis tells us that the five key building blocks for keeping well are:

Independence: Independence keeps people well – not the other way around. People tell us they want to be as independent as possible for as long as possible and they want to use health services as little as necessary. That is because being independent gives them control over their lives and enables them to do the things that matter in their lives (see **Enabling Purpose** below).

Mobility is a significant determinant of independence: Services and equipment that enable and preserve mobility and give people confidence about getting out and about is an investment in wellness. Likewise, long waiting lists for mobility aids and fear of falling when a person is out or about swiftly lead to rapid deterioration in health. Public transport and other forms of support e.g. home modifications, mobility scooters, wheelchairs, disability badges, falls risk assessments and safe pavements give people confidence and help them get out and about. Aiding mobility is an investment in keeping people well. Preserving mobility is an especially important health issue in rural parts of North Lincolnshire. When the relationship between health and mobility is understood this way, investing in mobility preservation will be critically important to delivering *Healthy Lives, Healthy Futures*.

Learning life skills – including **adopting positive coping strategies** - also contributes significantly to being and staying independent. When people become 'first time parents' and 'first time carers' for a spouse, parent or child with disabilities or chronic illness, they have a big 'life skills deficit' to address. If they learn new life skills quickly (ideally taught by someone who is an expert through experience), they - and the person they care for - will keep well and live independently. We also found children brought up under local authority care do not learn life skills and are not supported when they move out of the 'parental home'. This is often when their life often falls apart.

Enabling purpose: caring for others is most people's purpose. Children, family and spouses are the most important people we care for. Other things like gardening, sport, reading and learning also provide purpose for some people. Work provides a particularly strong sense of purpose



for those working in 'caring professions' like the NHS, care homes and teaching. Caring for others is a mixed blessing – both for those who care for a loved one and for those whose job it is to care. Because it is so fulfilling, caring keeps people going. It often also means that people neglect their own health, putting the health of the loved one they care for – or the people for whom they care professionally before their own health and wellbeing. Carers (including young carers) and the caring professions often put off seeking medical help until they are very ill. They are the high risk communities and people the NHS needs to be vigilant about supporting.

It is important that commissioners understand that work that provides purpose does not always have to be 'paid work'. Understood this way, services that are about enablement and independence should not be measured by success in getting people into paid work alone. A more useful measure that reflects value from a person's perspective is whether the person feels fulfilled and has a sense of purpose in their life. It is also important to recognise that for family carers who work, work is seen as a much needed break – respite in fact; because it provides a different kind of purpose – as well as access to strong social support (see **Strong Social Networks**). Working keeps carers well. That is why it is so vital that employers of those who combine work and caring are sympathetic and flexible. This work shows that the NHS and other public sector employers like schools 'could do better'. They need to review policies and the way they support employees who are carers to better juggle things – especially in times of crisis and rapid change. Public sector organisations cannot ask for flexibility and caring from major employers in North Lincolnshire if it is not a flexible, caring employer itself.

Strong support networks: people want to be 'independent' and choose how to live their life and care for their bodies. Simultaneously, they want to be co-dependent and have strong bonds and emotional support from people who listen, respect and understand them as a person – especially in times of transition and crisis to keep emotionally healthy. Overwhelmingly, people look to their friends and family first for this support. They also get a huge amount of value from being connected with people going through the same life journey or living with the same condition as they live with. This is equally so for people who care for a loved one and front line staff working in caring roles. The very clear message from this work is that commissioners should invest heavily in developing peer support across the board – including investing in peer support networks for front line staff who work in caring roles. People who act as mentors, coaches and buddies within such networks also get a huge sense of fulfilment (purpose) from this caring work (see **Enabling Purpose**). So this approach is a real 'win-win' investment in terms of keeping well. This work shows that older people in particular are keen to provide mentoring to others, based on their extensive life experience. We also found that many young people – especially those who have been brought up in the care system and those who did not have strong adult role models crave inspiring adults to look up to. Commissioners can invest in connecting people so they can help each other. People living in care homes are a neglected asset. They also want to contribute to this caring work – and they are desperate to meet new people. People



who are in recovery have a lot of wisdom to share – and not only with others who are before them in the recovery journey. They have overcome many challenges in their lives and have learnt how to choose positive coping strategies. There are many others who know they need to do the same. Parents of older children can potentially support parents of younger children. This work shows that in North Lincolnshire, there is an appetite amongst the community to support each other. Commissioners now need to invest in the infrastructure to harness that potential. Supporting the voluntary sector to build and develop peer support networks and leadership; investing in community building work (see APPENDIX THIRTEEN for contacts) should be central to the Healthy Lives, Healthy Futures commissioning strategy. This support should be commissioned in a robust way – to deliver a clear set of person centred outcome measures, based on what we now know matters to people and best practice in commissioning peer support. Connection with peer mentors should happen very early – and be integrated with statutory services like general practice and secondary care. Everyone in significant transition and following crisis or diagnosis should be offered peer support - because it provides so much reassurance and emotional support, which in turn means keeping well and remaining independent. However, commissioners must be clear. This is not a ‘free good’. It will require significant investment to operationalise peer support and mentoring at scale. In the long run, this investment will kick start a virtuous circle and pay for itself many times over and lead to a significant shift in service use - a reduction in unplanned urgent and crisis care – with people keeping well and living independently for longer. Commissioners can be reassured that this is what the community want. A consistent message is that commissioners should build the new care system by investing in managing and developing the rich seam of community good will that North Lincolnshire enjoys through volunteering.

Top 10 insights

1. Independence keeps you well. The NHS and social care tend to behave as if keeping people well keeps them independent. This work suggests that it is, in fact, the other way around and that preserving and supporting ‘independence’ (and as part of that – preserving mobility) is actually keeping people well. In this work, people define ‘independence’ as: being in control of my life, doing the things that fulfil me, being able to care for myself and my condition and being able to get out and about to see friends and family and do the things that fulfil me.

2. Mobility is major determinant of independence. Investments in 'mobility preservation' are not just about mobility aids and house adaptations – although these are important. It is also about things like: safe pavements, organized walking clubs, good public transport links and car sharing schemes, disabled badges and access – plus all work to prevent falls. This work suggest that there should be more investment in ‘mobility preservation’ and that commissioners should ensure there a minimal or zero waiting times for all types of mobility support for maximum commissioning impact on keeping well.



3. People who care for others – both those who work in caring professions (including front line health care professionals) and family carers – have much in common. Both put the health of the person or people they care before their own health and are prone to delaying seeking help with their own symptoms and health issues. This puts both groups at additional risk and means commissioners need to think about directing providers to identify and support them to keep well.

4. Conversely, the fulfilment both groups get from their caring work keeps them well. It is a fine balance. Both paid, professional and unpaid carers and the health professionals who care for them need to watch for signs that they may be approaching the ‘tipping point’ so that support is provided proactively and in advance to help them keep going and coping.

5. People who work in front line health care provision and caring roles in care homes perceive they have unsupportive relationships with GPs and feel their health concerns are being not taken seriously by their GP.

6. Peer support provided by people who are ‘experts through experience’ is an essential part of any wellness system. It needs infrastructure to support and embed it and it needs to be commissioned. It is not a free good and needs to be supported. The voluntary sector may be especially good at supporting peer support. Commissioners should commission for outcomes from support – not simply provide funding.

7. People and families do not talk about ‘integrated care’. They talk about the relationships with professionals contributing to keeping them well. Relationship based care systems keep people well. Relationships between front line teams and across organisations are part of this. It is relationships between people - not processes - that achieve integrated care. Commissioners should invest in building relationships instead of designing pathways and processes.

8. From the person and family perspective, being listened to, supported and understood by the teams who support them is key. Having one safe, trusted person to go to for reassurance who listens and deeply understands them as a person and their story (life context of their condition) is key. Knowing they are ‘there’ if needed is often enough.

9. Friends and family are the main source of emotional support for people. That is why it is so important to keep people connected with loved ones when they going through transition and to involve loved ones in planning and conversations about care. It is also the reason why those who have little social support are especially vulnerable to becoming ill and dependent. Peer support from people with shared experience is part of this support circle. It may be

more or as helpful to help people deal with emotional wellbeing issues.

10. Everyone needs to have purpose to keep them well. That purpose is often not paid work - although that is important for those who can find work. For most people that purpose comes from caring for others. This desire to care is an asset as there are many people in the community - especially older people - who want to contribute and care. Commissioners can invest in enabling this. It will enhance well-being within both those who do the caring and those who receive the care.

High impact actions for commissioners

These are the high impact actions that emerged from this work and what people say matters:

Patient and family experience

- Commit to and co design a relationship based care system – not a clinically defined one – in partnership with local people and communities
- Invest in building infrastructure and capability to enable everyone to benefit from peer support – at scale
- Invest in independence. This includes:
 - Helping people to share what matters to them in their life (purpose) and monitoring the value services add in terms of how they support people to carry on doing what matters to them
 - Prioritising investment in services and support that preserves mobility with short or no waiting times - because people need services immediately to preserve their health. This includes: home modifications, wheel chairs and mobility scooters, disabled badges, public transport and car sharing ‘buddy’ transport schemes, safe pavements, organised walking schemes and the falls prevention service.
- Focus on supporting care homes and residents to preserve mobility. Get resident out in the fresh air more – and give them more variety - including the chance to meet new people - and a sense of control over their lives
- Recognise the major life transitions people face; focus on co designing and delivering great experiences of transition

- Systematically deliver a personal relationship with the 'system' in the form of a trusted, safe person that the individual can turn to. Develop the workforce to ensure this is sustainable and that a range of people can fulfil this role – not just clinicians. Recognise the contribution of peer mentors and volunteers in supporting this relationship and providing reassurance and a sympathetic ear
- Given local public concern about maternity services, work with the community, midwives and health visitors and use this insights work as a trigger for a conversation about how to deliver a relationship based approach to maternity services, which sees a midwife (and/or potentially a doula) buddying a women right through to birth – wherever birth happens – and back home again
- Revisit parent's experience of advice and support - especially women who decide not to breast feed in light of how current services make them feel and the potential future impact on women's openness to seeking advice on healthy family eating
- Recognise as a community asset the life experience and wisdom of older people. Connect them with young people who want and need inspirational, older role models so both can help and support each other to keep well
- Provide on-going emotional support for people in recovery – especially around dealing with emotional loss and grief that surfaces after they cease substance misuse
- Explore with pharmacy teams and those collecting prescriptions and taking medication under supervision how the experience of pharmacy based care can be improved
- Audit the impact of the Discharge Lounge at Scunthorpe General Hospital on readmission; systematise transition out of hospital through the Discharge Lounge, which is adding significant value. Address the perverse incentives that are leading wards to bypass the Discharge Lounge
- Invest in a prototype rurally based Health and Well Being Centre, funded jointly by CCG and Council, with the local community supported to lead concept design and development
- Invest in developing GP practices as well being centres ('wonderlands') in Scunthorpe, building on best practice in other parts of the country
- Support all GP practices to embed new ways of working and organising work and access e.g. introducing group consultations for people with long term conditions (LTCs), practice led case and care management of people with 2 or more LTCs, development of volunteer

capacity linked to the GP practice to expand capacity, create practice based peer support networks and to undertake outreach and case finding (all these ideas that have been implemented successfully elsewhere in England)

- Scope evidence based community building approaches like 'Connecting Communities' (C2) that support communities to heal themselves in areas of the greatest health inequality. Invest in community building
- Provide more 'drop in' facilities to reassure parents with young children about health issues (especially urgent care issues) ideally based in Children's Centres
- Undertake an audit and identify places where hospital services can be provided in community settings; as demanded by the community, transfer some services within 3 months, thus sending a strong signal to the community that the CCG is listening and responding
- Expand organised walking schemes and family centred exercise activity programmes

Staff experience

- Share the findings of this work with senior managers at Northern Lincolnshire & Goole NHS Foundation Trust (NLAG) – and with front line NHS staff
- Use the findings to discuss staff morale, health and well-being with NLAG and other local NHS providers. Together, agree what needs to happen to keep the NHS workforce well – especially frontline caregivers. Build this into providers' 2014/15 'improvement contract'
- Review how the NHS employers, North Lincolnshire Council and local schools support staff with caring responsibilities; become exemplary
- Continue to apply commissioning approaches that involve front line staff. Ensure the results are fed back directly to front line staff: 'You said, we did'. Raise the profile of the CCG experience led approach to commissioning – explaining it is based on listening to and co designing care with front line staff and people who use services. Ensure staff feel they have permission to participate from their employer – including being freed up from their caring duties to participate in co design events
- Run more engagement and co-design events on site in NHS premises so people can contribute as part of their working day

- Discuss with NLAG and other providers how they are going to respond to the feedback in this work and systematises ways of working that empower front line teams and harness their enthusiasm and energy to improve things. Build actions agreed into providers' 2014/15 'improvement contracts'
- Agree set of outcome measures with Trust management around how they appreciate, recognise and value the great work front line teams already do. Measure the change in staff morale and feelings of empowerment – with a particular focus on people feeling respected trusted and in control of quality and improvement as part of performance management.
- Monitor levels of wellness amongst the NHS workforce
- Consider investing in further diagnostic co-design work with NLAG community teams and RDaSH mental health teams - and with workforce in general practice (and other primary care providers) - to find out how those who deliver front line care and those who run these organisations feel about keeping well
- Specify that providers put in place peer support for front line teams – especially those involved with delivering care directly to people and families - including support around dealing with grief and traumatic experiences
- Explore how opportunities to exercise can be offered during the working day e.g. organised lunchtime walking clubs, which would also provide an opportunity to talk, get peer support and provide the opportunity to get to know people in other teams
- Explore further and work with front line care givers and GP teams to find out why people who work in NHS services appear to have a less supportive relationship with their GP than the community more generally – and what can be done to improve this; co design an improvement plan with GPs and front line staff
- Explore with NLAG and other providers how primary care services can be made more accessible to the NHS workforce e.g. GP clinics held in Scunthorpe General Hospital for staff - and how staff can get easy access to other health screening initiatives without needing to take time off work
- Raise awareness amongst staff of the need to **'keep well to care'** and that an investment in their own health is really an investment in the health of the people they love and the people they care for at work. This is also an important message for family carers.



Person centred outcome measures

There is still more work to be done to define the person centred outcomes that will help commissioners leading Healthy Lives, Healthy Futures to track progress towards a relationship based care model that keeps people well. However, these are the ones we have identified to date:

Care (system) experience

- Improved experience of transitions (as per emotional maps)
- Improved experience of crisis in care (as per emotional maps)
- Short or no waiting times for responsive services that support 'mobility maintenance'
- Performance management of services around how they contribute to the person doing what matters to them (fulfilling purpose)
- Integration and systematic access to peer support
- Increased access GP appointments; easier booking systems – including on line
- Drop in advice at Children's Centres (or other easily accessible community venues) for parents looking for reassurance around urgent health issues

Person's experience

- I feel listened to, supported, respected, understood and treated as a person
- I feel confident and able to manage my condition and keep well myself
- When I need reassurance about health issues, there is someone I can talk to easily



- I have a 'safe person' **whom I choose** to be my contact to connect with about keeping well (not always or necessarily a health care professional). He or she helps me and my family to do the things that keep us well and independent and to stay on track when things are in transition
- I have easy access to peer support from 'people like me' with lived experience – if I want it. I learn from my peers. I am coping and managing my condition and keeping well as a result
- My caregivers recognise the importance of and support my emotional well being
- My caregivers understand what matters in my life (purpose) and work with me so I can do the things that matter
- I feel able to contribute my 'gifts' and care for others in of need support and help
- I feel supported by my employer to keep well
- My caregivers support me to stay connected with my friends and family
- I have the life skills I need to be a good parent, carer – to live independently

In addition to the above for carers:

- I feel supported by caregivers to keep well and cope with the challenges of caring for my loved one(s)
- I feel I am able to be an effective advocate for my loved one(s)
- I understand my loved one's condition and how to manage it
- As a carer I feel listened to, supported, respected, understood and treated as a person
- I feel supported by my employer to care for my loved one – especially in times of transition or crisis

In addition to the above for front line NHS staff:



- My employer provides opportunities for me to network with and get support from my colleagues
- I feel respected, appreciated and valued
- I feel involved in improving services and quality
- I feel listened to
- I have opportunities to exercise during the working day

It should be noted that the local community sent a very strong message that the NHS in general and CCGs in specific are placing too much emphasis on clinical outcome measures – and not enough on ‘experiential’ ones.

They want to work with the Healthy Lives, Healthy Futures team to change this – and to get involved in monitoring progress and the changes as they happen.

This energy is a big opportunity and asset for the Healthy Lives, Healthy Futures team to harness. Changing the balance around the outcomes to be measured will demonstrate commissioners have ‘big ears’; and want to work in truly collaborative partnership with the community.

We would suggest an early action would be to build on this community commitment and for North Lincolnshire CCG to use its local ELC practitioner team to run an Improvement Contract Co-Design Event (Co-Design 5 of the ELC™ Framework) with key providers (including NHS trusts, voluntary sector and GPs) to cement the Healthy Lives, Healthy Futures outcomes framework, building on the ideas in this report. To drive co-ordinated, relationship based care, the outcomes framework developed should be applied to all providers. This is exactly what ELC Co Design 5 is designed to do.



Background

North Lincolnshire CCG is working with North East Lincolnshire CCG and Northern Lincolnshire and Goole Hospitals NHS Foundation Trust to undertake a major service transformation programme, focused on creating a sustainable care approach. The success of this programme is predicated on people living independently and caring for themselves and their families well including adopting healthy lifestyles that ensure they have a low risk of, in particular, diabetes, and giving up smoking.

Underpinning redesign work are two principles:

- We want to maximise peoples' ability to self-care and live independently
- We want to focus on prevention and support people to recover and live independently.

In 2013, North Lincolnshire CCG decided to undertake an ELC™ programme to help it to better understand how it could support people to keep well to deepen its insight into how best to redesign of services to align with these principles.

Much of the engagement work that North Lincolnshire's commissioning organisations have undertaken in the past has focused on understanding people's experiences of medical treatment. This work is different in that it has set out to understand what needs to happen so people are confident about caring for themselves and can live well and independently.

This means asking a different question.

"What needs to happen in your community so that you and yours feel confident, keep well and live an independent life to the full?"

This work aims to help North Lincolnshire CCG to:



- Understand what local people and front line staff believe needs to happen so they have the confidence to keep well and live an independent life to the full - with appropriate and possibly very different types of support from health and care services;
- Describe what North Lincolnshire should invest in to realise this outcome
- Shape North Lincolnshire's priorities for investment to deliver this outcome
- Identify what local people would like to contribute/do for themselves to support their local NHS to achieve this goal
- To describe person centred outcome measures that can be used to track progress.

The people of North Lincolnshire

North Lincolnshire CCG covers 160,000 people. Based on 2001 census data, the people of North Lincolnshire are: 96% White British, with a further 1.3% being White Irish or White Other. The remaining 2.7% are Asian Pakistani, Asian Indian, Asian Bangladeshi or mixed race. This equates to approximately 4320 people. There is a small and growing population of Eastern European immigrants.



Methodology

This work aimed to engage with a random sample of a minimum 160 people in the groups identified by North Lincolnshire CCG as important, namely:

- Families with young children
- Older people
- Young people in education and work
- People who work in North Lincolnshire (with a particular focus on the public sector)
- People with mental health issues

to ask them about their current and desired experiences of keeping well; what matters most around keeping well – and what needs to happen so they can keep well and live an independent life to the full.

Building on existing insights

This work builds on relevant existing insights that North Lincolnshire commissioning organisations have already gathered. Based on the Bibliography within the Joint Strategic Needs Assessment (JSNA), North Yorkshire and Humber Commissioning Support Unit gathered copies of all insight work already completed by the PCT, CCG and Council. A full list of these insights is available on request. It is also included in APPENDIX ONE.

Because we were aware of existing work and insights, we did not focus in this work on: end of life or living with Long Term Conditions. Separate and specific ELC™ programmes have been completed to explore improving experience in these domains. We also did not focus on dementia as a CCG led ELC™ programme is underway looking in detail at improving dementia care.



We did not specifically set out to engage with carers as a major piece of work has just been completed to engage with, and assess, carers' needs undertaken by Circle, University of Leeds. However, we did speak to many family carers during our work.

Likewise, because a lot of work has already been done with people from BME communities, we did not seek out this group specifically. They are also a relatively small percentage of the people who live in North Lincolnshire. We actively sought to involve them by contacting the local multi faith partnership and presenting to them.

Existing insights were included in this analysis and have informed recommendations. Summaries of existing insights are also given in this report.

Getting programme design right first time; building on community assets

In March 2013, we held a strategic stakeholder co design event to present our proposed programme design; to ask for feedback and to help us to identify community assets to build on so we could get the best out of the resources we had to work with. The report of this event is provided as APPENDIX ONE. Based on feedback from stakeholders who attended, we changed our programme design quite significantly. For instance, we included an on line survey - see APPENDIX TWO for script - and we focused more attention on families with pre-school children and to talk to them in Children's Centres. The emotional touch points remained unchanged. They are described with a rationale for their selection at APPENDIX THREE.

North Lincolnshire local Healthwatch highlighted that they would support the 14 co-design conversations we had planned and so we moved forward in partnership with local Healthwatch. North Lincolnshire Council also offered to host an online survey – and this offer of help was also built into delivery and programme design.

We were also invited to an event with people in recovery in May and attended to talk to participants.



Programme Design

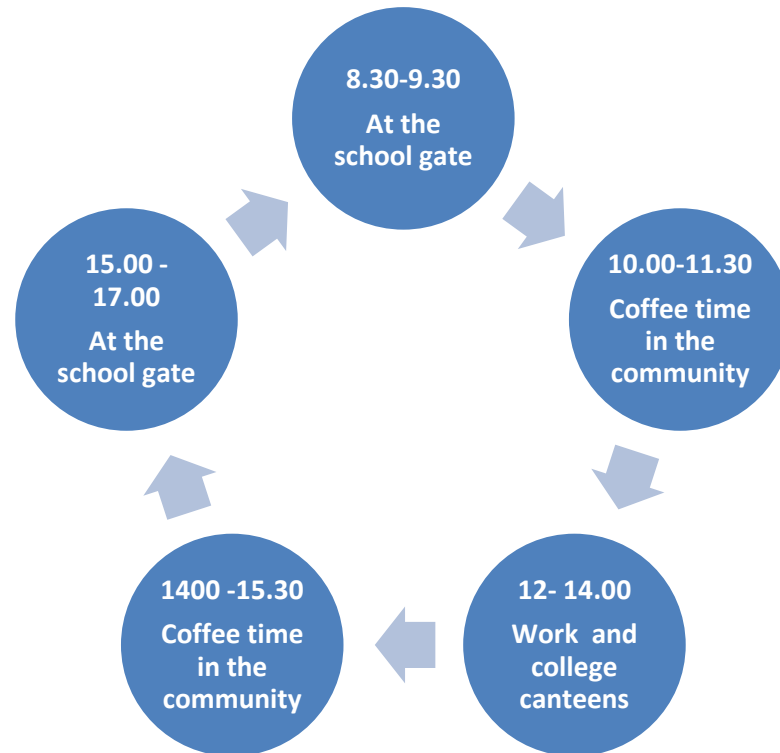
The final programme consisted of two phases:

Phase one: 14 co-design conversations looking at CURRENT and DESIRED experience of keeping well and independent living held in community settings with people who use and deliver services and an online survey

Face to face conversations included:

- The school gate (morning and evening) and parents evenings in primary schools and a school for children with disabilities (n = 3 events)
- Sessions at Children's Centres with different family groups (n=3 events)
- Visits to care homes and the Seniors Forum to talk to older people (n= 3 events). We also talked to care home staff
- A full day at Scunthorpe General Hospital talking to staff and people using services
- A lunch time session at Civic Centre, Scunthorpe with North Lincolnshire Council employees
- Session at Celebration Event for people in recovery
- Visit to Multi faith partnership
- A session in a GP practice in Scunthorpe.

Apart from those we talked to at the Recovery Celebration Event and in the hospital setting, we did not manage to engage with younger people in education or working. We also did not manage to gain access to talk to people who work in private industry in North Lincolnshire.



The on line survey is running to September 2013 when it will be fully analysed.

We reached over 200 people at 14 face to face events and collected thousands of insights. Analyses and findings from these conversations are available in APPENDICES FOUR - ELEVEN and have been aggregated into 8 community groupings. Findings are being fed back to each community – and passed on to relevant commissioning leads within the CCG, CSU and Council.

Phase two: co-creating a shared vision of a healthy community that supports keeping well and independent living

Phase two consisted of a PATH planning event where we invited a broad range of stakeholders to come together and to answer the question:

“What needs to happen so that people keep well and live an independent life in North Lincolnshire?”

PATH is a powerful, engaging visual planning approach that is deeply person centred and enables people to participate as equals. For more information, see APPENDIX TWELVE where the PATH event is reported in detail. It is also summarised in this report more briefly. Around 35 people participated. The group who attended were a 'microcosm' of the North Lincolnshire community and included some of the community champions appointed in April 2013. The voluntary sector was also well represented.

Outputs from this work

From this work we have generated to date:

- An aggregated analysis of people’s current and desired experiences with recommendations to North Lincolnshire CCG about what needs to happen (investment priorities) to help people keep well and live an independent life to the full and a set of proposed person centred outcome measures to track if services are delivering what matters most - this report
- Eight individual community analyses for: families with preschool children, families with school children, families with children living with disabilities, care home residents and staff, older people who live independently, people in recovery, people who use GP services, people who work in public services (Scunthorpe General Hospital and North Lincolnshire Council) – APPENDICES FOUR TO ELEVEN
- A PATH Plan with write up - APPENDIX TWELVE



Experiences of keeping well and living independent life

Introduction

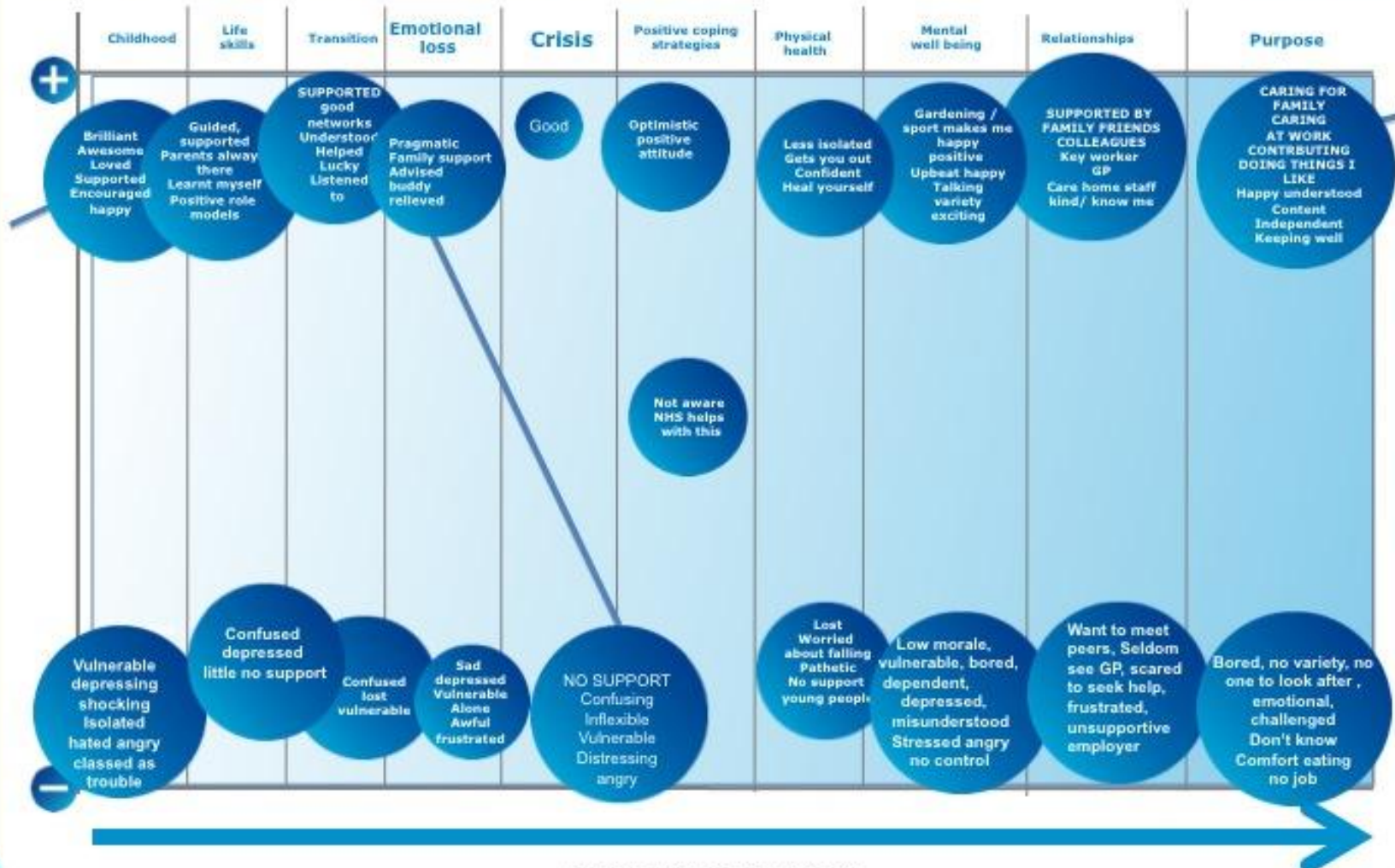
We talked to:

- Parents of pre-school children
- Parents of school children
- Parents of people with disabled children
- People in recovery from drug and alcohol misuse
- Older people who live in their own homes
- Older people who live in care homes
- People who use GP and hospital services in North Lincolnshire
- People who work in care homes
- People who work in Scunthorpe General Hospital
- People who work in Civic Centre (North Lincolnshire Council)
- Teachers

Current experiences of keeping well

The current population experience of keeping well in North Lincolnshire is captured in the emotional map below. Detailed descriptions of current experiences of individual communities are given in APPENDICES FOUR TO ELEVEN.

Keeping Well in North Lincolnshire Emotional Map: CURRENT EXPERIENCE: AGGREGATE DATA



The following summarises what people told us:

Childhood experiences and life skills: people tell us that they have mixed experiences of childhood and very mixed experiences of learning life skills. This work found a clear link between learning life skills and keeping well – and that learning life skills is not just limited to childhood. There was a marked intergenerational difference, with those who grew up before the Welfare State and during the war years, adopting an attitude hallmarked by greater self-reliance. This is in contrast to parents of preschool and school aged children who had often not learnt life skills as children. A deficit in life skills was exacerbated if the person had grown up in the care system or without positive adult role models. There is an indication from this work that the Local Authority can become a better ‘corporate parent’ and ensure children in its guardianship are well prepared for independent life. In the absence of this, they often turn to peers whose life skills and coping strategies may include crime and substance misuse. We also found that ‘first time parents’ and ‘first time carers’ need to learn new life skills as they face challenges they may not have faced – including navigating the benefits system and managing with a tight budget to eat well. Learning these skills from people who have ‘lived experience’ is invaluable; through a mentorship/coaching approach rather than a classroom based one. Teachers were mentioned frequently as role models and schools as a place where people could or had learnt life skills. However, more often and by far the most powerful influence are family; notably parents and grandparents.

Transition and emotional loss: this work identified a number of important transitions that people experience around keeping well and independent. How people are supported through these tough times impacts significantly on their emotional wellbeing and also on their ability to keep well and live independently. They include, from this work:

- ♥ Parenting your first child (with preschool years being a tough transition for many families)
- ♥ Leaving local authority care (cared for young children)
- ♥ Becoming unemployed/redundant
- ♥ Becoming a carer (of a child, spouse or parent)
- ♥ Progressing through early recovery after substance misuse (people in recovery)
- ♥ Discharge from hospital
- ♥ Retiring
- ♥ Adjusting to failing mobility or cognitive function
- ♥ Moving to a care home



- ♥ Bereavement
- ♥ End of life journey

Emotional loss is a specific transition and often a very difficult one for people. Bereavement (loss of a loved one) is the most difficult although losing a job – and stopping caring for someone (even though they may not have died) can also be experienced as a significant emotional loss. People also talked about separation from partners and spouses and miscarriages in terms of emotional loss.

People told us that services fail to support them through emotional loss. Friends and family are the main source of support. People want services to recognise the emotional side of their experience much more – and to support them emotionally during these difficult times.

We found emotional loss of a loved one featured heavily in the stories of those in recovery. They talked about how taking substances ‘numbed the emotional pain’ and how the pain resurfaced after they stopped. This was a key transition time when they were especially vulnerable and often services were stepped down at this point. People we talked to all wished services had reached out, understood what they were going through coping with loss and supported them when they were failing to cope well and starting to misuse. It would have saved so much heartache in their lives.

Crises in care are a consistent low point in people’s current care experience. People feel that they get no support from the NHS. They feel confused and have little understanding about what is happening – particularly to loved ones who are ill and particularly if they not the spouse of the person. They do not feel listened to or understood. The support they get comes from family and friends – not services. They tell us that often crisis could have been prevented. They feel like they need to ‘beg for help’ – and they want to be supported to keep well so that crisis care is averted. They say no one listens in the NHS until there is a crisis.

Positive coping strategies: people were unused to thinking about how they adopt and use coping strategies. They are more used to focus on negatives – are asked about stopping unhealthy habits – not building positive ones. Few people had been taught positive coping strategies by anyone. A notable exception was people in recovery. Because they could no longer turn to substances like alcohol, they had learnt positive strategies to cope with life’s up and downs. This learning through experience means that they are a huge asset and their life experience could be very valuable to many others we met – who have not yet found positive, healthy ways to cope.



People who work in Scunthorpe General Hospital reported high stress levels. They often found it hard to apply positive coping strategies – like exercising - because of shift work and the pattern of their day. They found talking to peers a hugely valuable coping strategy. Older people often engaged in volunteering as a positive coping strategy to provide variety and connection with other people. Services are currently focused on stopping bad habits rather than supporting people to address the underlying issues making them smoke or drink and build positive ones. People talked about benefits of yoga, walking the dog, talking to people and volunteering as positive coping strategies they used.

Mental and physical wellbeing: people told us that they were more focused on / concerned about their mental than their physical wellbeing. They also told us that getting out in the fresh air and exercising enhanced their mental wellbeing in particular. This was especially true of older people. Older people told us they worry more about dementia than their physical health. However, when their mobility fails, older people tell us it takes a huge toll on their mental well-being, with many reporting that immobility ‘gets them down’ and makes them ‘depressed’. People perceive services do a better job at supporting them to change their life style than to maintain their mental wellbeing. However, what people shared was that if their head was not in the right place, it was hard to change bad habits and keep well. This suggests that the emphasis in terms of keeping well may be the wrong way around – and it would be better to focus on ‘head and heart’ (in the emotional sense) first – and body second. People told us being independent and doing the things that give them a sense of purpose is an essential part of a healthy ‘head and heart’. That is why any investment in sustaining independence and mobility is so important to keep people well. It is when people can no longer do things for themselves that they become depressed – and their physical health then deteriorates rapidly. This means preserving mobility (public transport and other transport schemes, safe pavements, home modifications, disabled badges, organised walks, falls prevention, wheelchairs and other mobility schemes) need to be framed as investments in mental wellbeing and keeping well.

Relationships and peer support: relationships with family and friends are the most important thing around keeping well. They sustain people. Being listened to, understood ‘for who I am’, accepted in a non-judgemental way keeps people well. People do not feel listened to or understood by services. They often feel judged and not seen as a person. They are listened to and understood by family and friends. Those who have a small social network are vulnerable to becoming unwell and dependent.

Purpose: having a strong sense of purpose keeps people well and independent. It is what people live for. For most people, family and friends - and especially children - are their main source of purpose. Caring for others is a very strong driver for keeping well and independent. Those with no family to care for anymore look for often seek out someone to care for. Older people in particular are willing and able to play a caring

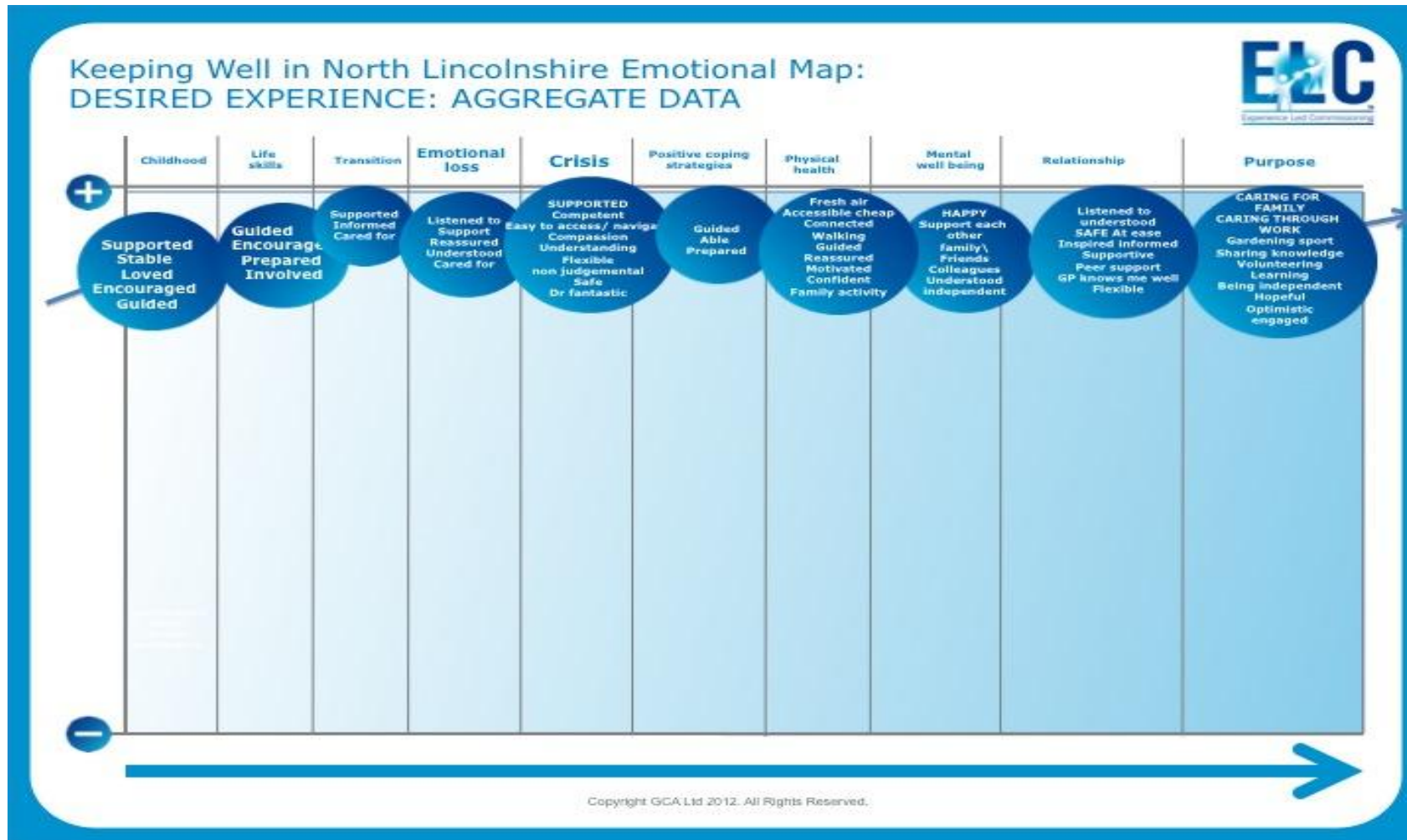


role with others. Care home residents we talked to all shared how they sought to retain their sense of purpose in various ways; often by caring for other residents.

Work provides a strong sense of purpose – not surprisingly, especially for those whose role involves caring for people e.g. teachers, people who work in NHS, care home support staff.

Being independent enables people to pursue their purpose. The two are inextricably linked. People say services do not understand or support them to continue to do the things they see as their 'purpose' (what matters to them) and do not work to support them to maintain that activity – even though doing so is key to keeping people well. Focusing in on and understanding what matters and working to support people to carry on doing what matters – and creating opportunities for people to care - would keep people well and independent for as long as possible.

Desired experience of keeping well





The emotional map above describes the desired experience of keeping well. The desired experience is very clearly articulated in the map and there were no strong outliers across the 8 different community groups. The level of congruence is high. This map provides commissioners with a very clear signal about what good looks like to work with. Detailed descriptions of desired experiences for each individual community are in APPENDICES FOUR TO ELEVEN.



What matters most around keeping well

Introduction

We talked to:

- Parents of pre-school children
- Parents of school children
- Parents of people with disabled children
- People in recovery from drug and alcohol misuse
- Older people who live in their own homes
- Older people who live in care homes
- People who use hospital services
- People who work in care homes
- People who work in Scunthorpe General Hospital
- Teachers

We asked them to respond to two questions around what matters most. This is the analysis of the aggregated findings. Detailed individual analyses for each community are covered in APPENDICES FOUR TO ELEVEN.

What keeps people well and living independently

We asked all participants:

“What is the most important thing that keeps you well and living an independent life?”

Having a purpose in life

Caring for others: For people who work in public services, carers, people in recovery, parents of pre-school, school and disabled children and older adults, having family, grandchildren, friends, pets – and most often children and spouses – whom you care for is the most important thing for keeping well by providing a strong sense of purpose. Those in care homes who are now ‘being looked after’ still seek to care for others – mainly other residents - to keep this feeling alive. Many older people have a lot to give and would like to care for others more. Many volunteer to fill this gap. Many parents of pre-school families – especially those with no older role model – want to feel cared for. There is an opportunity to create connections that will help different groups to keep each other well.

This work also suggests that those who have no-one to care for are likely to be especially vulnerable to becoming unwell and dependent. As well as understanding who within the population is a ‘carer’, this means we should also understand who has no one to care for – as they are also at risk. This new insight should inform standard data sets for risk stratification – and the CCG and Council should find ways of maintaining and creating caring opportunities for those without close family who want to care.

This emotional map data also shows that it is family and friends rather than the NHS that sustains people in times of emotional loss, crisis and transition. This reinforces the need to keep people closely connected with loved ones during crisis and transition as a safety net in times when they are vulnerable and unwell. This has implications for all aspects of care design – and most especially for visiting times in hospital.

Rewarding work and activities: whether it is paid or unpaid, people told us that they find work gives them a strong sense of purpose. This was especially true of parents and teachers at the school for disabled people and people who work in the NHS and care homes. Volunteering



provides similar rewards to older people and those in recovery. Volunteering was not something that parents of preschool and school children talked about.

Learning new things; doing things they enjoy: many people talked about ‘learning new things’ as giving them a sense of purpose and achievement. Doing things like: studying, gardening, reading, exercising, ‘banter’ and ‘getting out in the fresh air’ were common themes. Having access to organised family activities that involve exercise was important for parents with disabled and school aged children. Playgroups were important for parents of pre-schoolers.

Independence

The ability to make their own choices, live and think independently, as well as being able to get out and about ‘in the fresh air’ to meet and talk to people is mentioned by all groups as important for keeping well. This sense of being free to act and able to carry out whatever they believe their life purpose to be, as well exercising control over their life is critical to emotional and physical well-being.

Mobility in particular impacts significantly on independence and when it is lost, people become unwell because they become dependent. Good public transport also contributes to mobility and to keeping people well and connected with their social network (see next point). Maintaining a feeling of independence for as long as possible – and in care home settings too – is vital to keep people well.

In the past, the NHS has focused on maintaining independence as a means to reducing costs of the health and care service. In response to this insight, this paradigm now needs to shift in North Lincolnshire because people tell us that maintaining their independence and preserving mobility is the route to keeping well.

A strong social support network

Everyone mentions family and friends as being the most important thing that keeps them well. A strong support network of family or close friends provides a safety net – especially through the tough times in life (see emotional maps). With family and friends, people can talk, be



listened to and understood – accepted and seen for who they are by someone who knows them well. It is this sense of belonging that keeps people well.

This makes it important that people in care homes are placed as close as possible to family so they continue to visit and maintain their connection with the person – and commissioners need to recognise and enable this wherever possible.

It is also the reason that those in recovery tell us they did not feel they were in crisis when they were misusing – because they felt closely connected to and part of a community. It is why connecting people who have the same lived experience is such a powerful intervention to improve health and wellbeing – no matter what walk of life they come from. And it is the reason why many older people feel sad and depressed – because they no longer have this sense of connection to family and friends who may live some way away or have passed. It is also the reason why people who have grown up in care are so vulnerable and often fail to thrive, keep well and live an independent life into adulthood - because they may have few close friends, no family and so lack this support network. This is why they are also particularly vulnerable when they become parents themselves.

Investment in connecting and supporting people to build a strong social support network, keep in touch with family and friends and connect with peers and role models with lived experience of the same issues the person faces is a valuable investment in health, wellbeing and independence.

Healthy lifestyle

Respondents from all groups mention healthy eating and regular exercise as important around keeping them well. Mobility and independence impact on peoples' ability to exercise. Even those with limited mobility say they want more exercise.



What the NHS can do to support you

We asked all participants:

“What is the most important thing that you feel the NHS can do to keep you well and living an independent life?”

People want to do as much as possible for themselves and to use the NHS as little as possible because they are confident about how to care for themselves independently. However, when they need the NHS, these are the things they want:

Relationships, relationships, relationships

Responses show that for by far the majority of people, it is their relationships with people who provide services and sit within the system that matter most. The person who they have a close relationship with does not necessarily need to be a health professional. In fact, this work showed many instances when school support workers, teachers, key workers, play leaders, care home assistants or managers of refuge were the ones keeping people well and living independently. It is this relationship with a ‘safe’, ‘supportive’ person that is perceived as the most important thing. People want to feel listened to and supported by the system to keep well for themselves. They want to remain as independent as possible for as long as possible.

Services need to respond to this by focusing on building **relationship based care** that is personalised and enables the person and family to enjoy an on-going relationship with someone they trust who listens and supports them.

The NHS and other public services (and private sector employers) also need to apply this same standard to caring for employees; in particular the public sector needs to become a listening, supportive, flexible employer that helps the people who work in front line caring roles to keep well.



A more personal care experience

Another key theme is delivering a personal care experience. Parents of preschool, school aged and disabled children, older people in all settings and people in recovery all wanted a better experience of their clinical consultation with health professionals. People want the NHS to be more approachable, understanding, a safe place to go for help and advice which is and non-judgemental - and to be treated as an individual with respect and sensitivity. In particular people want there to be time for professionals to listen to their concerns. People do not feel listened to currently.

Several groups also mentioned the importance of feeling reassured that the NHS would be there for them when they needed it – like a safety net. This included people wanting reassurance the NHS would remain free.

Better communication so that people feel informed about their condition, services and care - and about where they need to go for advice is also an important part of this.

Along a similar line, staff from Scunthorpe General Hospital wished the NHS would treat them with respect and show appreciation of the work that they do, whilst also listening more closely to their concerns. This was especially true in relation to their own health and their family caring responsibilities.

Peer support – interactions with others with shared experiences:

Older people, people in recovery, parents of pre-school, school aged and disabled children directly expressed a wish to be connected with others in a similar position to themselves. People felt that peers understand and empathise with them and can offer more practical help and guidance on the day to day challenges and successful coping strategies than professionals – because their advice is real and comes from a place of deep understanding of what they are going through.

Parents of preschool children wanted older role models to look up to for inspiration. Those in recovery said being connected to those who were further along their recovery journey was important in giving them inspiration and hope.

Older people craved the opportunity to share their wisdom and missed caring for others

Parents of preschool children we talked to in Children's Centres shared how being able to go to places where they could meet other parents and where their children could socialise was very important. Other groups echoed this and talked about creating meeting places and peer support groups; something they felt the voluntary sector was especially good at facilitating.

Amongst hospital staff, the desire for peer support manifested itself in a call for recognition of the importance of having 'protected space for staff to network and support each other', which would allow them to share their experiences with others who have been in similar circumstances and really understand their viewpoint. Many talked about the support they get from their team and peers informally.

Consistency of care

Directly expressed by parents with disabled children and preschool children is the desire for consistency in the people delivering their care e.g. being able to see the same GP. The important thing about consistency is that it allows people to build trusting relationships and feel 'understood'. This supports the delivery of a more personal care experience because the provider knows, in depth, what their specific needs are. Consistency makes it possible for the NHS to get to know the individual as well as their health issues.

Service redesign: more person centred care

Parents of preschool, school and disabled children, and Scunthorpe General Hospital staff expressed ways in which the NHS can be redesigned in order to better serve their needs and run more efficiently – especially around urgent care needs. These ideas included: increased access and availability of 'drop in' services for advice, treatment and reassurance – especially for parents of young children ideally delivered in Children's Centres and other places where people already are, a GP working in the hospital running a clinic for staff. They also expressed a desire for services to talk to each other - joined up communication.

Essentially, the majority of respondents are suggesting ways in which the service could become more person centred, and thus better serve their individual needs rather than serving 'delivery of targets' and the system's own administrative processes.



Interestingly, the one group who did not suggest system redesign were older people. In general they were more focused on changes that the NHS needed to make to their personal care, rather than changes to the system as a whole.



Existing insights from other communities and commissioning work

Introduction

Using the Joint Strategic Needs Assessment as the starting point, we identified all the existing insight assets in North Lincolnshire and provided a list to the engagement team at the Commissioning Support Unit. They requested copies of these and sent them through for review. We have used the following resources, which included insights relevant to this work:

- 'You said, we did' report (no date)
- Let's talk: review of adult services (2012)
- Support needs of carers in North Lincolnshire (2013)
- Mental health review BME communities (2011)
- Experience led Commissioning programme End of Life Care (2013)
- Experience Led Commissioning Programme Outpatient Redesign (2013)

You said, we did

The key findings from this report of relevance to this work were:

People said:

"We just need a bit of support to help people organise stuff ourselves... more health and wellbeing activities"

"We are isolated in Haxey. We do things for ourselves because we have never had services in the first place."

People want:

- To walk more – not alone – in organised walking groups. People with mobility problems are inhibited from walking because of dangerous pavements
- Clearer information about the benefits they are entitled to
- More training opportunities, including apprenticeships
- More information on early signs of disease
- Health checks like ‘over 40s check’
- ‘hands on’ practical support about managing their health and to do more for themselves
- More help with smoking cessation
- Better access to GP appointments
- Easy to follow signposting to lifestyle change support
- Young people to learn life skills: eating well, work ethic, sexual health, money management, parenting skills
- More family activities
- More activities for children to do / play together.

The assets described in the report that can be built on include:

- Expert Patient Programme
- Ironstone Centre as a place where cooking classes can be/ are held
- Breast feeding road shows and peer supporters
- Family nurse partnership
- PLINGs; physical activities programme aimed at older children
- Health Trainers
- MEND sessions; physical activities programme to address childhood obesity



- Cook and Eat sessions
- Health improvement facilitators in 5 localities
- Pharmacists
- 20 organised walks in North Lincolnshire

Carers

“I am caring for my husband. I really need someone to care for me! I always say to my children, ‘when Dad is ‘sorted,’ will look after myself. I like being independent – not needing any help. I won’t let carers in the house. I don’t want someone coming in and doing things for me. I don’t like to bother my family – but I get into trouble if I don’t, I get lots of visits from my family. It gives us someone to talk to. I know My family were worried about me. My husband doesn’t give in to pain easily. I knew he wasn’t well. I didn’t want to call my family. It was a Bank Holiday - and they need a rest on holidays. I didn’t want to take him to hospital where he would lie on a trolley. I think he had had a mild stroke. When my son came he said I should have rung hospital because he was so ill. I had pains. I know I am not well. I have been putting it off. (first name) my GP came. He knows me really well. He told me to go to hospital straight away. My husband is still there. I am waiting for my son to pick me up. What would keep me well? I am not sleeping because of my husband being in pain.... When he moves, it wakes me up. It is also hard lifting my husband, what I would do for a good night’s sleep.”

This carer’s story was shared with us during one of our 14 co design conversations illustrates well many of the challenges carers face keeping well and living independently. Many of these same challenges were identified in the Circle research¹ and are recognised as common experiences of family carers.

We spoke to many people with caring responsibilities in the course of this work, including people who work for the NHS and public sector organisations who are family carers, spouses of people who live with LTCs – and of course parents of children and disabled children. We did not specifically seek carers out - because North Lincolnshire CCG and Council recently commissioned this substantial piece of work from Circle

¹ Circle research



to complete a needs assessment with carers in North Lincolnshire. Circle spoke with 230 carers in the course of their work. Their final report was reviewed as existing insights to inform this work. We also drew on national insights from the Royal College of GPs; Commissioning for Carers resource².

The key insights that we found to inform this work from the Circle report AND from our own conversations with carers are outlined below:

- People do not see themselves as ‘carers’ and so it is hard to identify them and support them
- Caring takes its toll on financial health. Carers are unaware of welfare benefits and local ‘carers payments’
- Carers are wary about respite care. They are scared and reluctant about leaving loved ones with others. They need lots of reassurance about quality. The FIRST respite experience really matters to build trust. Many carers do not know about the local ‘breaks service’
- People want flexible support (training), ‘carer life skills’ and support managing personal/medical care. There is training they can tap into; but there is poor uptake. It needs to be offered in various ways as carers may not be able to attend class room training; mentoring may also work well
- Carers want greater / in depth understanding of loved ones’ health conditions so they can care and advocate well. They feel ignored by health and care system, which does not see them as an asset and an important care integrator/enabler.
- Carers ignore their own health needs and focus instead on the person. Often this means they seek help too late and become ill. The same is true of caring professions who put people above their own health. Carers are a HIGH RISK GROUP
- In North Lincolnshire, there are great local assets to build on. The voluntary sector - especially the Carers Support Centre – is a hub and facilitator to build a peer and support network to support carers/families to keep well and live independently
- Being able to work keeps carers well. Understanding, flexible employers are critical – and the public sector, which is a major employer, leading by example is important. Currently people say the public sector ‘could do better’
- Siblings in families with disabled children play an important role in supporting parents and grandparents. We need to notice their needs and support them

² RCGP commissioning for carers resource

- First time parents and first time carers of older people with long term conditions (often adult children or spouses) need to learn new life skills to become successful, resilient carers; accelerating their learning of successful coping strategies will keep them well. Peer mentors and buddies are especially valuable in this regard
- In 64% of unplanned hospital admissions family carer break down is a contributory factor³
- Not having any one to care for is also a significant risk factor for becoming unwell and dependent.

This work highlights a real paradox around caring for family and being a professional carer

On the one hand, people tell us that caring gives them a strong sense of purpose and keeps them well and happy. Those who have no one left to care for actively seek out opportunities to care for others and contribute e.g. older people.

On the other hand, those who are experiencing 'intensive caring experiences' and responsibilities retain the fulfilment they get from this sense of purpose and reward from caring – and it keeps them going. However, as the intensity, physical and emotional burden of caring increases, people can become overwhelmed or experience symptoms of illness that they usually ignore. We found in this work that: first time parents; parents who have not learnt life skills and/or have little family support and those caring for older parents and spouses with LTCs, including dementia are especially vulnerable. We also found that this same behaviour is also occurring amongst people who work for the NHS and in caring professions. This means they are also a high-risk group.

Because caring simultaneously keeps people well and puts emotional and physical strain on them that causes health issues, it is not surprising that people often cope for a long time (both family carers and NHS staff) before seeking help.

It also alerts health, care and voluntary sector services to be more sensitive to this paradox and help people and the 'system' to spot the 'tipping point' so we can support carers and help pre-empt crisis and keep them resilient. These insights should inform design of carer support and can potentially be used to help create more sensitive needs assessment tool. NHS staff should also be assessed regularly around their support needs.

³ RCGP commissioning for carers resource



People from ethnic minorities

NHS North Lincolnshire commissioned Apna Sahara Ltd to deliver four focus groups with people from BME groups in North Lincolnshire. The purpose of these focus groups was to identify attitudes towards emotional wellbeing and mental health services. The four focus groups composed of: Eastern Europeans, Chinese, South Asian women and BME men.

Similar themes emerge amongst the immigrant population as we found in the other 8 communities we worked with. There are no surprises.

'Staying healthy' emerged as very important to this group. It increased their ability to support and care for their families and the opportunity to work. All groups mentioned that being with and talking to family and friends, along with exercising was instrumental in maintaining their emotional wellbeing and mental health.

What keeps these groups happy were relationships and being with people they care for, as well as knowing their loved ones were in good health and happy themselves. Social contact and being close with friends and family keeps them well and happy. As we found with the other communities, relationships are instrumental in keeping people well.

Mirroring others communities' feedback, the immigrant community commented on the lack of joined up communication between health care professionals. They specifically do not feel well informed about mental health, GP and dentist services.

This group's criticisms of the NHS largely revolved around culture sensitivity issues. Some participants worried they were being misinterpreted by health care professionals because of cultural mannerisms may be misunderstood. This was particularly true of the Chinese people who felt their cultural mannerisms - such as speaking very loudly - could be misconstrued as rude or aggressive, which led to them having a poor experience of the NHS. This poor experience can result in reluctance on the part of people from this community to access NHS services until the health situation becomes critical.

Translation issues were also of particular importance to this group. They wanted the NHS to support them and their families with accessible drop-in advice sessions with no language barriers (translation present) and cultural awareness. One suggestion was walk-in healthcare services provided with translation at regular, well-advertised time slots during the week for unplanned urgent care matters; potentially situated at the new primary care centre in Scunthorpe. A desire for quality translation mirrors the importance other groups had placed on developing a



relationship with health care staff and being treated as an individual, which would obviously be impossible for those whose English is weak if they and the health professional they are talking to are not able to understand each other easily.

Adult social services

The aim of this work was for the North Lincolnshire Council (social services commissioning team) to hold a conversation with the people of North Lincolnshire to understand what support people currently value; what things they would like to improve and to understand how people could best be supported to live life to the full. In January - April 2012, 158 responded to the on-line survey and a number of focus groups were held. The findings resonate closely with the findings in this work.

The top five themes that emerged as important to people in being able to live their life to the full were:

- Getting out and about
- Living in their own home
- Independence
- Social contact and activities
- Staying in touch with family and friends

When asked what was working well to deliver this, people mentioned the following:

- Personal budgets are making a difference to choice and control
- Support from health professionals
- Support from home carers. Many people mentioned the support of this group.
- Advice and support from adult services.

There were no concerns regarding feeling safe.



People said that the personal budgets help them to maintain independence and control over the way they live their lives.

Many people told commissioners that they relied on family carers for support. People who were not yet receiving support also told commissioners that family and friends would be their first line of support.

People felt they needed to remain involved in their community and contribute to it. A theme of loneliness came through in responses. Maintaining people's involvement in their community and family life through community activities was important. Having a say in services and control over their lives through initiatives such as the personal budget also mattered. Transport was raised as an issue for people. It was felt that transport was not frequent or flexible enough, leading to increased feelings of isolation amongst people.

Some people could not find the things they were looking for. Commissioners recognise they need to ensure people are able to find information more easily.

Some people raised concerns about what would happen in an emergency situation. Commissioners are now working to ensure that all service users have contingency plans in place as part of their support plans. Concerns were also raised about the amount of time paid home carers spend carrying out their visits. A review of the commissioning of home care contracts is looking further at this issue.



End of life

The synergies are striking between this data and what we found in the Keeping Well work:

Current experience of people and families:

Everyone feels that there is a problem with the quality of end of life care in North Lincolnshire - and no one is talking openly about it. This makes it hard to improve things. The current culture does not support conversations about death and dying, which means the issue does not get raised when it should. Palliative care is seen very much as a specialism rather than 'everyone's business'.

Currently there is no systematic approach to anticipatory planning in end of life. Where anticipatory services exist, access is limited to be people with a specific diagnosis - most often cancer. Those with other diagnoses and frail older people nearing end of life do not get anticipatory care. People and front line staff do not feel there is choice or a systematic, person centred approach to enable people and families to articulate their wishes for end of life - although tools do exist (My Life, Alzheimer's Society). More anticipatory care is needed - and advanced planning especially for people with dementia.

Hospital is not a peaceful place to die. There is a current issue with Scunthorpe General Hospital discharging people at the end of life back to their homes at short notice (including at weekends) without adequate community based support being in place. People at the end of life are admitted to hospital the same way as everyone else. Too many are admitted when they could potentially have a peaceful death and be kept comfortable at home (including in care homes). There is poor communication between Scunthorpe General Hospital and specialist tertiary centres.

People feel alone and as if the system does not empathise with their situation or give them the time they need when they are on an end of life journey. The same is true of carers of people at end of life who have no professional support, are not listened to and are very vulnerable to becoming unwell themselves.



People and carers do not feel involved in decisions about care. Care does not feel holistic and little investment is made or attention paid to supporting the emotional journey at end of life – neither for people themselves nor for their families. The value of alternative therapies is not recognised as part of this emotional well-being support. People find it difficult to access information about services that are available.

People crave connection with those who are going through the same life experience. There are not enough peer support groups and ways to connect people so they can help each other; not enough befrienders nor enough creative use of volunteers.

Current staff experience:

Front line staff feel overwhelmingly 'frustrated'. This saps energy and motivation. Frustration is creative energy with nowhere to go. It is a huge waste of resources. They perceive care as even less co-ordinated as the people and families experiencing it do!

They feel the biggest challenge is building relationships and trust between front line professionals. This is an even bigger priority than sorting out information and record systems.

Standards of care are mixed and highly dependent on the motivation and life experience of the front line professional and caregiver.

To improve quality, staff say the NHS needs to consistently support staff (emotional support and continuing professional development) and improve patient experience; especially in relation to caring for people with dementia - and including the general practice experience, which they say is mixed.

They feel nurses should be more involved in sharing bad news, which often a traumatic experience for people and done badly by doctors. District nurses and allied health professionals are assets to build community-based end of life care with. Community based capacity is desperately needed.

Staff feel uncomfortable talking about 'choices' with people as they fear raising expectations and they do not believe there is any choice currently.



The hospice and the 'Pink Rose Suite (DPOW)' are valued and seen as key assets - as are support groups in Barton.

Desired experience of care:

This is highly congruent with delivering the Keeping Well recommendations.

We will have succeeded when:

“Everyone recognises the need to improve end of life care. It is accepted as a ‘journey of improvement’ here in North Lincolnshire; one where we will ‘mend the potholes in the road as we go’ and consolidate and build improvement - rather than expecting to achieve a paradigm shift overnight. This work will be reinforced by a county-wide campaign, focused on changing culture so that talking about death and dying is easier and we see it as 'everyone's business'. We will invest in enabling front line teams to forge relationships to support delivery of co-ordinated care and build community based capacity.

From the person and family perspective, people now feel as if they are ‘conducting their own orchestra’ around end of life. They have a clearly articulated, person centred ‘My Life’ plan that encompasses all aspects of their desired experience and supports them to prepare with their family for a good death. The system responds to this and is held to account for delivering the outcomes that matter to people and families. Family carers feel supported, listened to and involved in the development of this plan. The plan is ‘like a parachute that ensures we land well’.

People at end of life have access to community based care 24/7 through a single access point, with this experience feeling joined up.

People's meet their emotional needs with peers and caregivers with whom they have a close relationship. Care is holistic and provided in welcoming, comfortable surroundings, there is good signposting to services. Peer support, befriending and volunteering are well developed. Front line staff feel supported (emotional well-being and CPD) to support and deliver consistently good quality care. Doctors and nurses work together to break bad news well. Health professionals recognise and give time to those on an end of life journey with empathy. There is continuity of care (relationship based care) wherever possible.



Outcomes and performance management processes recognises the experience people say they want to have (for full detail of this vision, see End of Life PATH Plan) and services are directly accountable to the people who use them for supporting delivery - with 30% of quality assurance processes being co-produced with those who use the services. Commissioners feedback to users directly about how things are changing and improving as a result of their feedback.

Outpatient care for people living with long term conditions (LTCs)

Once again, there is great synergy with the work undertaken around outpatient care experience for people with LTCs and what we found in this work.

Current experience of people who use outpatients:

People do not differentiate between inpatient and outpatient care - it is all 'the hospital' to them. This is a significant reputation management issue for North Lincolnshire and Goole Hospital Trust (NLAG) as outpatient experience is very mixed.

People who use outpatients and staff view outpatients as the 'poor relation' and dumping ground. There are pockets of good practice – notably the diabetes team and very poor practice (eye clinic), which is described as 'chaos'.

People say that going to outpatients is a frustrating experience that adds little value. It is often unclear to them why they need to go there. They don't always recognise a clinical benefit from attending. Feedback from staff would suggest that this perception is often valid and there is no benefit (see staff experience below). Often people wait hours for tests; appointments are cancelled or they arrive and no one expecting them. People find telephone contact with both clinics and transport services difficult.

People say they learn nothing to help improve their ability to self-care and manage their condition at outpatients. They get bored waiting. People feel that the 'social platform' created by a long wait with people who live with the same condition as they do in outpatients is ignored and underutilised. They appreciate volunteers who work in the hospital and support and direct them.



No one tells them why they are waiting or how long they will be waiting for. This makes it impossible to plan – and difficult to get food and drink. They often wait a long time for transport home. This is especially problematic if they are diabetic - although transport staff anticipates this and are well prepared and able to give them some food to keep them going.

Going through the Discharge Lounge improves experience of waiting for transport. Even if it is a long wait, at least it is a nice place to wait.

Often people going to outpatients have mobility issues - so getting to outpatients situated at the back and in the middle of the hospital is difficult. It is long walk from car park and the front door. Going to cashiers office to get transport costs reimbursed on a separate floor and to pharmacy is difficult too. The discretionary period to get back to the car is too short for people who walk slowly. Some people choose to go to Hull rather than Scunthorpe for car parking reasons alone.

Current staff experience:

Again, front line staff feel deeply frustrated. They feel they are over-burdened with paperwork that adds no value to care quality. They have too little time to spend with patients. Both staff and people feel frustrated by cancelled appointments.

Staff say when people do see a doctor, often no decision is taken about the next step in care e.g. no decision to discharge because the consulting doctor does not know the person and does not feel confident about discharging them from outpatient care. They also say that consultants never apologise to patients when they turn up late. They say that aggressive behaviour from patients towards staff goes unchallenged. They find liaising with community staff and social care especially frustrating.

Outpatient staff can't book transport for patients, which leaves them feeling guilty and powerless and as if they abandoning people.

Desired experience:

Outpatient staff and people agree that they want the experience of outpatients to be designed from the person' perspective. This work has clearly articulated a good experience for people (for more detail see Outpatient PATH Plan) where:

- People get information in advance of attending - a leaflet with everything they need to know - including: a single number to ring with queries about transport and the appointment; a map of where to go and how to get the outpatients, travel options to get to hospital

including the best place to park closest to outpatients; an indication of how long they are likely to be there plus details of catering facilities so people can prepare and bring food and drink with them if needs be.

- It is easy to ring with queries about appointments and a human being talks to you (described as a 'bat phone')
- When they arrive, because of clear signs and support from volunteers who meet and greet people and show them the way, it feels easy to reach the clinic
- Thought goes into planning appointments around the person i.e. an afternoon one if they live a long way away; all on the same day if they live with multiple conditions. People also want tests done before they attend (at GP surgery ideally) to reduce waits on the day and so clinicians have all the information they need to act and take good decisions
- Decisions are made - including discharge – without delay
- People have someone they can talk to if they have a query about symptoms or their condition in between visits/ post discharge
- Visiting outpatients is a learning experience - somewhere they can connect with people like them and other experts e.g. voluntary sector organisations, welfare advisors etc who can help and support them to manage their health and life better and keep well and independent.
- Food and drink is readily available with potentially a 'beeper system' in place so they can go to another part of the hospital and get back in time for their appointment (this has already been trialled and worked well)
- Staff have less paperwork and are able to order transport for people. They want the area used currently for people to recover post chemotherapy to be developed as a comfy place where people can relax, wait and learn about their condition. They want more use made of the Discharge Lounge

Everyone wants NLAG senior managers to sit up and take notice of outpatients now. They want them to realise that outpatients is NLAG's shop window to the community. What happens in outpatients impacts on NLAG's reputation within the community - and colours peoples' expectations of inpatient care. People want to see NLAG invest in a new environment and experience; building outpatients as a learning hub. This need not be expensive. Volunteering will be key. NLAG does need to invest in human resource to co-ordinate and build volunteering capacity however.

People also want to explore how more outpatient care can happen in the community and only attend when doing so adds value. Also, a specific focus on improving experience and care co-ordination for about 160 frequent users is needed.



The synergy we found between existing insights and the findings in this work gives us confidence that we have identified the essence of what matters to people around keeping well in North Lincolnshire.



A shared vision of great care: PATH planning work

Introduction

In June 2013, we held a strategic planning event with the local community. Commissioners, providers, people who use services, carers and the voluntary sector were all represented. Some of the people who participated in the Phase 1 co design conversations also took part in this planning event. Others joined for the first time. The event was facilitated by local ELC™ practitioners and the local Healthwatch team, working with groups of around 10 people. It was led by an ELC™ PATH process and PATH graphics facilitator. The process invited the participants to work together to ask:

“What needs to happen to create a health system that supports keeping well and living an independent life in North Lincolnshire in 2015?”

The full report of this event is produced as APPENDIX TWELVE.

Our ambition for health and wellness in North Lincolnshire

First the group described their ‘ambition’ – the no holds barred dream of a perfect health system to keep them well and support independence. This is what the group described:

“To keep well and living an independent life, people want to feel as if the health and wellness service is designed to be a ‘circle of support’ for them and their families. In this new landscape, everyone speaks the same language; there is no prejudice and everyone is seen as an equal.

There is a healthy local economy so that people have resources available to them and an occupation that keeps them well (not necessarily a paid job). Everyone feel they have a purpose and are making a valuable contribution to their community.

There are no hospitals – because they are no longer necessary. There are also no politicians interfering with the way the system works. Because we now work so differently, there is time and money to invest in keeping well – and people providing the service feel very proud they



are doing such a great job. We have redrawn the delivery of health and wellbeing services across North Lincolnshire. We call it 'The North Lincolnshire Keeping Well Map' (image of this is captured on the Keeping Well PATH).

On the new map, there are affordable transport links across the community and well-established 'transport buddy up' schemes so people who are regularly making a journey can take others with them. People all have a safe place to live. Public transport and housing are now recognised as essential building blocks to keeping people well and living independently.

Instead of hospitals there are 'T J Hughes' style Health and Well Being Centres (HWBCs). They are like T J Hughes because they have everything you need to support you to become a knowledgeable expert in keeping you and yours well and living independently.

There are HWBCs across the county; with the concept adapted for both rural and urban settings. HWBCs are linked and they link in with and reach out to people proactively; especially those who are vulnerable and who do not have strong support network of friends and family.

Linked to the HWBCs are teams of volunteers who support people to come together and support each other. A new type of 'care professional' works in this new landscape. They are a person with BIG EARS for listening to what matters to people in a non-judgemental, supportive way. They also have a BIG HEART and are able to empathise and show compassion. They have BIG HANDS. They wear 'goalie gloves' and carry a 'safety net' so that they can catch people before they fall. They also wear Mortar Boards on their heads, signalling that they have lots of KNOW HOW – and the right skills and knowledge to support people to keep well and live independently.

Because people and families have learnt how to take responsibility for their own health and well-being, people now feel in control. It feels like people work with the new system - talking with those who work to support them; being understood and supported – rather than the system doing things to people."



A possible positive future by 2015

Next the group thought about how far towards their ambition they would be by 2015. They described their 'positive possible future' in 2015.

"The work completed in 2013 in the course of the 'Keeping Well and Living an Independent Life' programme had a fundamental impact on the thinking of local commissioners in both the local authority and CCG.

It was immediately fed into the Joint Strategic Health Needs Assessment. It underpinned and shaped proposals submitted to the NHS England Pioneers for Health bid in June 2013. It shaped thinking and how the consultation for Healthy Lives, Healthy Futures happened from July 2013 onwards in North Lincolnshire. The people involved in the work got copies of the write up and analysis quickly. They were kept involved as work moved forward. The community contributed fully to all future thinking around Healthy Lives, Healthy Futures.

There were some commissioning decisions that seemed incongruent to local people, given the insights generated and findings of the work done in 2013 – especially around young people's services and maternity services. In light of the findings of Keeping Well, local commissioners reviewed commissioning intentions to ensure that services adding value in terms of what people say matters and keeps people well was preserved.

By 2015 and by working together, the community in North Lincolnshire has already made great progress towards its shared vision of an integrated new health and wellbeing system across North Lincolnshire.

Different ways of delivering the vision of the new health and well-being service are developing in two distinct communities: rural settings and Scunthorpe. This is because people now understand that to achieve outcomes across the board, we need to build services differently and respond to the infrastructure and fabric of the rural community as well as more urban settings.



Health and Well Being Centres (HWBCs)

Central to the design of the new landscape is a growing network of HWBCs. These are places where you can go to chat about all sorts of things and get help with anything that relates to keeping well and living independently. The work done in 2013 informed concept design, especially three building blocks of 'keeping well' the work described.

The design of the HWBC has been community led (see **Bold Steps** below). These are not necessarily health centres. The menu of services they deliver (depending on what the community says matters to them to keep well and live independently) includes:

- Treatment services (including alternative therapies)
- Information and signposting
- Dental services
- Community building teams
- Peer support and listening / befriending services
- Volunteering opportunities

A big part of the work of the HWBC is enabling peer support. People who are happy to help others and who have lived experience of keeping well, managing their own health issues and overcoming illness and other life challenges (experts through experience) support their community and peers. Help can be quite simple. For instance, if someone is scared to go to the hospital on their own, someone will go with them.

HWBCs are also playing an important role in supporting a radical drive for quality improvement in end of life care in North Lincolnshire – especially for older people. People can go to the HWBC and talk to someone – and have a really safe conversation about all sorts of issues concerning them around death and dying. This openness is really enabling people and the community more generally to change how it thinks about end of life. It is helping people to open up and articulate how they want their end of life experience to be – and the health and social care system is now rapidly responding to this and creating flexible services that deliver to what matters to people at the end of life. This means that the CCG is making rapid progress on implementing its end of life strategy, developed in 2013.



This new thinking is also being extended to how the local Council plans the transport system. People who go on regular journeys now offer to take others with them e.g. weekly shopping trips to the supermarket. The co-ordination of this is funded. This is helping people who find it difficult to access transport – especially in rural areas - to keep mobile and connected. It is also helping the environment and reducing transport costs.

At the centre of the new system is also a very different attitude towards and use of technology. There is a clear single point of access. It is a 'red button on a bat phone' that connects people – especially vulnerable people - directly to someone who can help, advise, support, listen and guide them – especially when they are in transition or fear they may becoming unwell. This person can help work out what public services are available and get them rapid access if they need it. There is also an integrated information hub online – just one place for everything. It is also a phone application.

People with complex care needs also now have an 'iPAD' that holds their integrated care record. They have been trained to use it by volunteers – and it is transforming people's sense of control over their health (this idea had already been piloted in other areas of the UK in 2013). It is preventing unnecessary hospital admissions. It paid for itself within 12 months.

There is also a pilot underway for a 'chip' that people who are vulnerable have implanted that monitors their risk of becoming ill; a bit like a formula one car. When something is going wrong with their 'engine', the chip alerts them and they can go and get checked out.

In tandem, Integrated Health and Social Care teams who were in early stages of development in 2013 are now embedded and working well across all localities in North Lincolnshire.

Because checks ups reassure people, those who are especially vulnerable are now contacted on a weekly basis just to 'check in' and see how they are doing – not necessarily by a medical person. Use of technology underpins this.



Rural settings

In rural settings, work began immediately in July 2013 with the community and those who had already started to think about the idea of a Health and Well Being Centre (HWBC) to undertake a pilot – with a view to replicating it. The focus was very much on working with the assets within the community – existing buildings and even working out of people’s homes. Not having special premises did not hold people back.

In 2015, the pilot is complete and the CCG / Council is reviewing the findings and looking to replicate and spread the model across rural settings at scale.

Alongside that, campaigns aimed at linking people together to support each other and build community were also put in place quickly. One was around keeping warm and checking on your neighbours over the winter of 2013/14. As a result, people in rural communities are now more connected with their neighbours.

Linked to HWBCs, teams of people with ‘BIG ears, hearts, hands and know how’ are now in place. Because not all these people are doctors or medical people, people are now getting used to the idea that they do not always need to see a doctor when they feel unwell. Today in 2015, they often go to the HWBC first – or have ‘face time’ with an expert on their IPAD – especially vulnerable people who find it difficult to get out and about. It is working really well.

Scunthorpe

In Scunthorpe, the same vision has been pursued. The way it has been realised is very different however. In Scunthorpe – because they represent enduring and already funded community assets - a greater emphasis has been placed on building health and well-being community around GP practices. Practices are reframed now as ‘wonderlands of well-being’ – places where you can go to connect with the community and keep well. This concept builds on pioneering work undertaken in 2012-13 in Halton CCG where this approach transformed general practices into wellbeing practices.



It is a bit like that in the Outpatients Department and the Discharge Lounge at Scunthorpe hospital as well – with all sorts of activities going on in these existing hubs to support wellness. This was achieved by implementing the commissioning strategy the CCG developed in 2013 around Outpatient Redesign with local people.

Bold steps

Bold steps are the game changers. They are the brave actions and decisions that if we take them now, will accelerate our progress. There are three bold steps that the group wanted to see happen. There was a real sense of urgency from the group. They wanted to see action taken quickly to improve things in North Lincolnshire.

Early wins in shifting services to the community

People were keen to see services shifted very quickly away from hospitals and closer to home – especially in rural areas; within months.

People felt that there were community venues that would be suitable for services to be provided from – and that commissioners needed to start noticing these with intention to shift services into the community.

The assumption would be to make use of what is there already more efficiently rather than to build new things. A first step was to undertake an audit and ‘assets mapping’ exercise to identify places where hospital services can be provided in the community. This audit could include and was not limited to GP premises. There was an appetite for quickly agreeing with hospital partners the specification of premises needed to deliver different services e.g. a respiratory clinic, a diabetes clinic, physiotherapy sessions – and then to start looking for premises that meet this specification already. People wanted the shift to start changing things quickly.

Being a CCG with ‘big ears’ that listens well

The group had a specific set of requirements that would show the CCG had grown ‘big ears’:

- FEEDBACK! FEEDBACK! FEEDBACK! – tell us more ‘You said. We did’

- Update the accuracy of your ‘black book’ – stakeholder map and address book. Make sure you have the right contact details for us so we know what is going on. Keep in touch and use our preferred method of communication – email, post
- Invite us to all the events you hold in a timely fashion so we can attend and invite other people to come along too
- Make the website more accessible and engaging. Post invitations to events on the website; have live conversations happening on the website; share what you have done to respond to what people say matters: ‘You said. We did’
- Have a monthly communication with us. Some suggested a newsletter; others a meeting. All agreed there needed to be a regular way of keeping the community updated what the CCG is doing
- Use local media and existing news letters to have a conversation with local people
- Create safe spaces for the community and CCG to come together for positive conversations about improvement
- Be responsive - community led and focused. Stop being so ‘medical’ in your thinking.

People were clear that a CCG with big ears would give the community the feeling as if both parties were having a conversation and on-going dialogue – with the CCG demonstrating through its actions that it is listening, learning and doing things differently because of what people say matters.

The group also described work to create new outcome measures (see chapter **Person Centred Outcomes**). People suggested measuring routinely the value services are adding around keeping people well and independent and said that the CCG should be looking at how it can use the hundreds of interactions with local people that happen every day in GP practices and hospitals already to do this.

This would require the CCG finding ways of connecting with people using the system so there is an on-going, live ‘conversation’ between the CCG and local people about how things are progressing towards creating a system that supports keeping well and living an independent life.



A community led prototype Health and Well Being Centre ‘with teeth’

Everyone agreed that developing a network of Health and Well Being Centres (HWBCs) would be a crucial feature on new ‘Keeping Well Map’ in North Lincolnshire. People had even started to design the menu of services that it would provide (see **Positive Possible Future**). The community wanted to see a pilot quickly. Within the next 18 months something should be up and running. One organisation had already submitted a bid to the Council for a HWBC in Scunthorpe and was awaiting feedback about how that would be taken forward.

There was a strong sense from the group that it was, in fact, rural areas that lacked this kind of resource most and that connecting rural communities through a HWBC was a really big priority. Recognising that we need to work with what we already have, people felt that in terms of buildings, we needed to think outside the box and look at existing community buildings like community hall, schools – and think about renovating and co-location before new build; even looking at whether people would host events and gatherings in their own homes.

People felt strongly that they wanted the design of the concept to be community owned and led. The group wanted to see a very different way of taking this work forward; with the CCG and Council setting a budget and providing a project manager to work with the community and with the work to co-design the HWBC led by the community – so it truly belonged to and was designed to cater for what matters to people - and incorporates the ideas of those who would be using it at the very earliest stage. People felt this would be a very explicit way in which commissioners could demonstrate that they trust the community to know what is best for itself.

The group agreed that those who had already done thinking on this around a HWBC in Scunthorpe would work with others who had ideas about the rural setting to take this forward and present a proposal to the CCG and the Council for a pilot – ideally in a rural area.

In line with this, the group also wanted to work with commissioners to understand best practice in community building – and to invite people who are working in this field and have achieved transformational change and healing within communities, applying community development approaches. A list of such organisations with contact details is available at APPENDIX THIRTEEN.



Analysis and ideas for commissioners and providers

People told us the essence of keeping well is quite simple:

“To keep well, I need to be able to live as independently as possible so I feel in control and can pursue my life purpose (which may well be caring for others), supported by a close social network of family, friends and supportive peers who share and understand my experience. I want one main trusted contact with whom I feel safe who is linked into or within the health and care ‘system’ (not necessarily a clinician). I want that person to respect me, listen deeply and support and guide me. I want them to join up conversations between services – especially during times of crisis and rapid change in my life - so that I can concentrate on coping and keeping well; doing as much as possible to care for myself with support of my family and friends. This person also needs to understand my story and see me as a person. My mental well-being impacts on my physical wellbeing – and vice-versa. Preserving my mobility is especially important because it’s about me staying in control and being independent. The NHS has to recognise and invest equally in helping me maintain both my physical and emotional well-being to keep me well. Often talking and being listened to by peer mentors and ‘buddies’ helps me with the emotional stuff - more than clinical people do.”

Everyone we talked to wants the same thing. They just need support to a greater or lesser degree, depending on the stage of their life they are at. If the health system in North Lincolnshire health and care services were to deliver this experience systematically for everyone, working in partnership with people and their families and friends as equals, it would maximise the impact of its support around keeping well.

Being independent keeps people well; not the other way around. When services align and deliver what people say matters, health services will be used less. A consistent message from the community is that commissioners should build the new care system by investing in managing and developing the rich seam of community good will that North Lincolnshire enjoys through volunteering. The second is it is all about relationships – and not necessarily with health professionals.



To move towards alignment with what the community says matters, commissioners need to:

Focus on co-designing and optimising transition and crisis experiences

“It feels like until you hit crisis, health services aren’t listening. You have to beg for help. When you are in crisis, you feel unsupported.”

How well a health care system manages transition indicates how person centred it is. It is during times of transition and crisis that the system is tested to see if it really understands what matters to people. The major transitions that emerge from this work are:

- ♥ Giving birth
- ♥ Parenting your first child (with preschool years being a tough transition for many families)
- ♥ Leaving home or local authority care (cared for young children)
- ♥ Becoming unemployed/redundant
- ♥ Becoming a ‘first time carer’ (of a child with chronic health or learning issues, spouse or of a parent)
- ♥ Progressing through early recovery after substance misuse (people in recovery)
- ♥ Discharge from hospital
- ♥ Retiring
- ♥ Adjusting to failing mobility or cognitive function
- ♥ Moving to a care home
- ♥ Bereavement

Currently the system does not respond to what matters during transition and crisis in North Lincolnshire. This work has described in detail great crisis care and support through transition from the perspectives of different communities (APPENDICES FOUR TO ELEVEN). The desired experience is broadly the same for all. Commissioners need to use this deep insight. The next step is to direct providers to work with front line staff and people who use services to co design the detail of sustainable delivery models – and measure progress by agreeing a framework of



person centred outcomes and measuring the outcomes that matter to people (see **Person Centred Outcomes**). A common outcomes framework across all services would be best to drive integration around the person.

Feedback at the PATH planning event indicated that local people have the appetite to lead work around outcomes measurement and paints a picture of some of the work that the community feels needs to be undertaken to improve things. The insights from this work take commissioners a long way towards defining 'good'. Now effective tools to measure progress will be needed. These may have to be designed locally if no suitable tools already exist. Work to scope existing tools will need to be undertaken.

Commissioners also need to be sure they build on the under-utilised asset that is Scunthorpe General Hospital's Discharge Lounge. Investing in an audit to look at readmission rates of people who have been discharged through the lounge would evidence the value it adds. Expanding and systematising the discharge process so that The Discharge Lounge can add value to more people who are transitioning out of hospital care is a wise investment. This work will also require the perverse incentive wards have for not referring to the Discharge Lounge to be addressed.

Focus on 'relationship based care' and not clinical integration

The NHS is very focused on 'integration' currently. The word integration was not used once by anyone we spoke to in this work – apart from by people who work for the NHS.

What people say they want is a safer, more trusting relationship with the people who care for them. When the person has a close relationship with someone who supports their care –and front line teams have close relationships with each other and permission to act in the best interest of the person - integration around the person happens easily.

Family carers are also critical to relationship based care. They are literally the 'other half' of the person – even if they are an adult child or friend of the person. They need to be seen as part of the person; listened to, trusted, respected and included. They have very valuable insight to share around the person's health issues. They often co-ordinate care and are an invaluable asset to the person and themselves keeping well and independent.

To support relationship based care, commissioners need to:

- ♥ Set outcome measures that track progress on involving carers as equals in all decisions; make sure policies around confidentiality enable this
- ♥ Put more emphasis on people having a 'choice of the person' as their main source of support with the system. The quality of the relationship with the person - not their job title - is what matters. The person needs to be someone they feel they can trust and build a close relationship with. If it is not working out, people need permission to say so – and it needs to be easy to change. This is especially important in relation to key workers and counsellors/talking therapists – and for those supporting older people and parents of preschool children
- ♥ Build a relationship based care support approach around pregnancy, birth and early years with consistency of midwife right through to birth – regardless of where birth happens - and health visitor support. Consider developing lay support for mums to be e.g. by investing in doulas
- ♥ Focus on building capacity and capability amongst those who are non-medically qualified so they can offer effective relationship based care, support and signposting. People tell us the 'link people' who currently add the most value and deliver the best relationship based care are not clinicians. They are: paid carers, key workers, play leaders, support workers, school outreach workers, care home assistants, managers in refuges. Trained volunteers and job seekers looking for work experience may also have a potential role to play here. There is a potential to develop apprenticeship schemes (which are funded) to create training opportunities for these 'link workers'. People who are in recovery could be skilled up and supported into employment through such an apprenticeship. By skilling up this group and enabling them to become a formal part of the new relationship based care system, it will reduce the burden on GPs and hospital teams and enable them to focus better on delivering great crisis care and extra medical support during transition

- ♥ Recognise that people who ‘misuse’ urgent care services are most often seeking reassurance. This new breed of ‘link person’ can help provide reassurance. A more relationship based care approach may have a significant impact on reducing urgent care use – especially amongst parents of young children and if it support family carers to keep going, cope better and keep well
- ♥ Collaborate with and invest in capacity in the voluntary sector to create and sustain peer support networks at scale. These will support people working in statutory services to deliver the relationship based care system. Focus the work of the voluntary sector most especially on people who are transitioning through major life changes and/or living with long term conditions or caring for someone. Build on existing community hubs like schools, Children’s Centres, Carers Support Centre, workplaces (including NHS workplaces) and GP surgeries and run peer support networks to operate from these hubs
- ♥ Commission all providers – including the voluntary sector to deliver outcomes. Apply an overarching person centred outcome framework that all providers work to and that is focused on keeping well and living independently, building on insights generated from this work (see **Person Centred Outcomes**)
- ♥ Build on the capability that people in the community already have – especially older people and others who may have been overlooked or undervalued in the past. Work with the voluntary sector and statutory providers to harness their energy and willingness to care and contribute to deliver this relationship based care system and the change programme to make it happen. The relationship based care system will create many opportunities for people to contribute and care to others. This will keep them well
- ♥ Identify people who are not well supported by a circle of close family and friends. They are vulnerable to becoming unwell and dependent. Risk stratification processes should measure and take this into account. Their ‘link person’ should work first with them to build their confidence and support them to develop a positive, robust social support network. This is the most valuable thing to keep them well. Well developed peer support networks will facilitate this

- ♥ Make sure that NHS and other public sector organisations are good employers who invest in looking after their staff wellbeing and support front line teams to support each other through peer support initiatives
- ♥ Prioritise investment in supporting front line teams who work together across boundaries to talk together. This will also develop relationships that ensure care integrates around the person naturally and easily
- ♥ Make sure employment policies of public sector organisations support family carers and are enabling – especially in times of crisis and transition.

Prioritise investment in sustaining independence and enable people to continue fulfil their purpose

“Current services don’t help us to keep well and live independently”

“I want to care for someone and make a difference to my community. Don’t write me off”

- ♥ Understand the interplay between independence and keeping well. Independence keeps people well – not the other way around
- ♥ Recognise mobility as a major risk factor for ill health and dependence. Include it in risk stratification processes and invest in ‘mobility preservation’. Understand that many services contribute to mobility preservation, including fall prevention, housing adaptations and public transport
- ♥ Reframe investments in mobility preservation: falls prevention, public transport, disabled access, disabled badges, mending pavements, home adaptations and mobility equipment, organised walks as investment in independence – and therefore a direct investment in keeping well

- ♥ Talk less about ‘falls prevention’ and more about preserving or maintaining mobility. People are very scared of falling. When we talk about falling, that is what people see in their minds’ eye. When we focus on the positive frame – preserving mobility ‘keeping you on your feet’, it will make people feel more confident, safer and focused on the desired, positive outcome
- ♥ Reduce waiting times and improve access for all the above services. This is an issue raised by people in this and other work. Commissioners must now recognise and understand that waiting times (often years) for these services is a false economy. Once mobility is gone, it is extremely hard to regain. Loss of mobility is often followed by a rapid decline in health. Responding quickly with risk assessments and providing mobility aids will keep people well for longer. There should be zero tolerance for waiting times
- ♥ Make sure assessment processes capture ‘what matters to the person’ around keeping well and independent - so that services know what matters and are clear about what they are working with the person and family to achieve. Commissioners should measure achievement and judge value added by services based on delivery of person specific and person centred outcomes e.g. I want to be able to get out and walk my dog; I want to see my grandchildren once a month; I want to meet new people and make friends. Expansion of personal budgets would facilitate this
- ♥ Help those who may have lost their purpose to regain a sense of contribution – especially older people (including those in care homes); people with disabilities; people who are unemployed or have been made redundant and people in recovery who have not yet found a way to contribute. Understand that successful contribution may not mean ‘working in paid employment’ for everyone – and that contributing in a meaningful way is very important to keeping well – including amongst those who have retired. Make sure that performance measures commissioners apply are not limited outcome measurement to paid employment
- ♥ Devise and spread schemes to connect younger and older people (including those in care homes) so they support each other



- ♥ Work with care homes to explore how to build on the assets residents have to contribute and how through community outreach, care homes can work to create variety for residents – with connection to new people and more outdoor activities / visits
- ♥ Invest in peer support networks at scale to help people support each other to maintain independence.

Minimise new investment in clinical services. Do different things and things differently - within the same budget

People clearly say they to use health service as little as possible and ideally less - with potentially one exception. They do want improved access to GP services. They do not want more services. They want services to behave differently. Most of the change is about people having a different attitude that signals they are listening to and supportive of the person.

People who work in the NHS (and especially those who have recently joined from the private sector) tell us that the NHS remains inefficient and there is a lot of waste. Working with front line staff (who tell us they want to be more involved in improving things) to redesign services at scale; being brave and supporting providers to get rid of all processes that are not adding value to patient care or contributing the purpose of the NHS – keeping people well and living independently – and reinvesting savings in creating peer support and relationship based care is the bold move that needs to happen at scale.

Note: in recent outpatient redesign work, staff also suggested getting rid of paperwork to free up time to care. Another recommendation was to build capacity through volunteering and work experience schemes. Progressing this could provide a small-scale model for critically appraising the value paperwork adds – and would be an early win.

Those delivering front line care also need to understand how people perceive their behaviour so they are motivated to change. The insights in this report and appendices will provide food for thought to trigger discussions with many groups of front line staff. Front line staff in Scunthorpe General Hospital need to hear that the people we talked to said they had experienced great care.

Invest in supporting people to build life skills – especially during major life transitions

“The life skills you learn determine your ability to keep well – as do the positive coping strategies you are able to adopt. Role models who have ‘seen it and done it’ provide the best support and inspiration”

- ♥ Children brought up in care may not have learnt sufficient life skills. The local authority as a commissioner of care needs to ensure that all children in its guardianship successfully learn life skills and are supported through transition to independent living by the time they leave care – just as good parents do. This work describes a vision of great parenting that can inform this work
- ♥ People need to quickly learn new life skills after some important life transitions e.g. setting up home on your own for first time (a particularly important transition for looked after children), becoming a ‘first time’ parent, becoming a ‘first time’ family carer (for a child r spouse with a LTC; for an parent), adjusting to life in recovery for people who have stopped misusing, retirement, bereavement. Those who accelerate learning of these life skills (including finding and adopting positive coping strategies) will keep well
- ♥ People say role models with lived experience who can mentor, coach and inspire them are more helpful than formal teaching in regard to learning life skills. People who can share their life stories and lessons help people learn the most. Older people and those who have been through a recovery journey are amongst the people who have valuable life lessons to share
- ♥ Supporting development of capacity and capability to enable mentoring and peer support (see previous recommendations) will provide a pathway to support people to learn life skills. A focus on role modelling and teaching life skills can be built into peer mentoring training
- ♥ Some young mums feel ‘judged’, ‘guilty’ and ‘unsupported’ with advice around nutrition if they choose to bottle rather than breast feed. They perceive there is no support for them to feed their baby well. This needs to be explored further and addressed as it may impact on mum’s openness to advice about diet and healthy eating later

- ♥ 'Cook and eat' sessions at Children's Centres are highly valued. Teaching people to cook healthy food on a tight budget is a life skill that many lack. More work in this area is a good investment in keeping people well – especially parents of preschool children and young people setting up home. Carers who often see their income drop may also benefit

Focus on community building, wellbeing and prevention

- ♥ Prototype health and well-being centres in rural areas (see **A Shared Vision** for detail)
- ♥ Explore how to build 'well-being practices' within GP surgeries in Scunthorpe (as model in Halton CCG)
- ♥ Build on existing, highly successful 'community spaces' that still have capacity to support health and well-being e.g. Children's Centre and Carers Support Centre. Use for many purposes – not just their designated purpose
- ♥ Explore application of proven community building approaches in the most challenging communities to help communities heal themselves e.g. C2 (currently working in North East Lincolnshire)
- ♥ Understand the contribution having a safe place to live plays in keeping well
- ♥ Link peer support networks and mentoring schemes to the health and well-being centres – focus on supporting self-care and maintaining independence
- ♥ Offer more 'drop in' services – especially for parents of preschool children and school children
- ♥ Build on pharmacies as hubs for support
- ♥ Review pharmacy experience of people taking supervised medication, which this work indicates was not currently a person centred experience.

Value emotional well-being as highly as physical wellbeing

- ♥ Recognise emotional loss – especially in children – as a significant risk factor prohibiting keeping well and a transition that can have devastating consequences on life and health if people do not get early support; with those who are socially isolated and do not have strong family support most vulnerable
- ♥ Explore new models of delivering emotional support and mental health care that are community based, peer led and coproduced with people with lived experience, supported by clinicians / those with a special interest where necessary. De-medicalise emotional support

- ♥ Provide choice of person - so people can find someone they trust and can build a relationship with – including talking therapies
- ♥ Recognise the emotional needs of front line NHS staff and support them
- ♥ Recognise the need to provide emotional support for family carers so they remain resilient

Make it easy for people to exercise - ideally organised walking and talking

- ♥ Exercise benefits emotional and physical well-being and so is particularly important to keeping well
- ♥ People in North Lincolnshire mainly want to walk – with other people. This was highlighted in the report 'You said; we did'. This stated that there were 20 organised walks across North Lincolnshire. So many people (especially older people) told us that getting out in the fresh air really matters to their physical and emotional well-being that this does not seem like enough action. Some creative thinking and commissioning could create some very sustainable solutions
- ♥ NHS staff wants opportunities to exercise within their working day. Organised walks are a quick and simple way to do this – especially as Scunthorpe General is situated just near a park. Walking and talking would also help staff build supportive peer relationships
- ♥ Different community groups want different kinds of walking and other activities: older people, families with disabled children, families with young children, care home residents. Cater to their specific needs

Think about access in primary care (especially GP) services

- ♥ People consistently say they have problems accessing their GP and that appointment systems are user unfriendly and difficult to navigate. People want to book appointments online and have different options
- ♥ Parents want reassurance and to be able to 'drop in' and discuss their concerns. There may be better ways to support parents to deal with children's health issues than through their GP e.g. Children's Centres are viewed by parents as a key source of support
- ♥ There is a definite issue with NHS staff and other front line caregivers like care home staff getting access to supportive primary care services. This work tells us that like family carers, they often go to the doctor as a last resort. There is also evidence that they do not feel listened to nor their health concerns taken seriously by GPs. This is concerning because this work suggests that like family carers, they are a high risk community.
- ♥ Parents of preschool children also say GPs do not listen to their concerns

- ♥ Commissioners and NLAG should consider how to increase access to primary care for front line staff - potentially onsite in the hospital. This work suggests that there are high levels of latent ill health (mental health and physical health issues) amongst NLAG employees. A holistic approach to health improvement amongst staff is something that commissioners and providers need to invest in to sustain services and improve health and well-being in North Lincolnshire. This is essential to maintain the resilience of the local NHS
- ♥ Care home residents also get poor access to primary care and especially GP care. Many are scared to ask for help when they feel ill for fear of what the GP will say. Feedback from staff at Scunthorpe General Hospital suggests that many unplanned admissions are from care homes. Care home residents are a group of people with complex needs, on an end of life journey. Commissioners need to take action to embed a proactive, relationship based approach to supporting care home residents to keep well – including ensuring appropriate levels of primary care support and preventative case and care management toward a positive and peaceful end of life experience
- ♥ GPs and primary care generally needs to pay special attention to family carers, those working in caring professions and those in life transition
- ♥ There needs to be more focus on building accessible support with mental health issues in primary care. This work suggests peer led models would be the best
- ♥ The community want to see services shifted quickly to the community from the hospital. Their challenge to commissioners: audit suitable premises – think outside the box and not just about GP surgeries – and shift some services within three months.

Many of the services people say they want from primary care do not need to be provided by GPs themselves. Again, it is about doing things differently. There is a need for commissioners to work with GP practices and support them to provide care in different ways that build relationships and peer support e.g. group consultations, building and integrating volunteering and peer support networks into GP practices, working differently with health visitors and district nurses. There is an opportunity to explore more co-produced approaches to primary care delivery. Some practices have already pioneered this, like Pathfinder Healthcare Developments, Halton and Newcastle West CCGs (contact details APPENDIX THIRTEEN). Peer mentoring and support linked to practices will be an important way of building capacity.

High impact action for commissioners

These are high impact actions that emerged from this work and what people say matters:

Patient and family experience

- Commit to and co-design a relationship based care system – not a clinically defined one – in partnership with local people and communities
- Invest in building infrastructure and capability to enable everyone to benefit from peer support – at scale
- Invest in independence. This includes:
 - Helping people to share what matters to them in their life (purpose) and monitoring the value services add in terms of how they support people to carry on doing what matters to them
 - Prioritising investment in services and support that preserves mobility with short or no waiting times - because people need services immediately to preserve their health. This includes: home modifications, wheel chairs and mobility scooters, disabled badges, public transport and car sharing ‘buddy’ transport schemes, safe pavements, organised walking schemes and the falls prevention service.
- Focus on supporting care homes and residents to preserve mobility. Get residents out in the fresh air more – and give them more variety - including the chance to meet new people - and a sense of control over their lives
- Recognise the major life transitions people face; focus on co-designing and delivering great experiences of transition
- Systematically deliver a personal relationship with the ‘system’ in the form of a trusted, safe person that the individual can turn to. Develop the workforce to ensure this is sustainable and that a range of people can fulfil this role – not just clinicians. Recognise the contribution of peer mentors and volunteers in supporting this relationship and providing reassurance and a sympathetic ear
- Given local public concern about maternity services, work with the community, midwives and health visitors and use these insights as a trigger for a conversation about how to deliver a relationship based approach to maternity services, which sees a midwife (and/or potentially a doula) buddying a women right through to birth – wherever birth happens – and back home again

- Revisit parent's experience of advice and support - especially women who decide not to breast feed in light of how current services make them feel and the potential future impact on women's openness to seeking advice on healthy family eating
- Recognise as a community asset the life experience and wisdom of older people. Connect them with young people who want and need inspirational, older role models so both can help and support each other to keep well
- Provide on-going emotional support for people in recovery – especially around dealing with emotional loss and grief that surfaces after they cease substance misuse
- Explore with pharmacy teams and those collecting prescriptions and taking medication under supervision how the experience of pharmacy based care can be improved
- Audit the impact of the Discharge Lounge Scunthorpe General Hospital on readmission; systematise transition out of hospital through the Discharge Lounge, which is adding significant value. Address the perverse incentives that are leading wards to bypass the Discharge Lounge
- Invest in a prototype rurally based Health and Well Being Centre, funded jointly by CCG and Council, with the local community supported to lead concept design and development
- Invest in developing GP practices as well being centres ('wonderlands') in Scunthorpe, building on best practice in other parts of the country
- Support all GP practices to embed new ways of working and organising work and access e.g. introducing group consultations for people with long term conditions (LTCs), practice led case and care management of people with 2 or more LTCs, development of volunteer capacity linked to the GP practice to expand capacity, create practice based peer support networks and to undertake outreach and case finding (all these ideas that have been implemented successfully elsewhere in England)
- Scope evidence based community building approaches like 'Connecting Communities' (C2) that support communities to heal themselves in areas of the greatest health inequality. Invest in community building
- Provide more 'drop in' facilities to reassure parents with young children about health issues (especially urgent care issues) ideally based in Children's Centres



- Undertake an audit and identify places where hospital services can be provided in community settings; as demanded by the community, transfer some services within 3 months, thus sending a strong signal to the community that the CCG is listening and responding
- Expand organised walking schemes and family centred exercise activity programmes

Staff experience

- Share the findings of this work with senior managers at NLAG – and with front line NHS staff
- Use the findings to discuss staff morale, health and well-being with Northern Lincolnshire and Goole (NLAG) NHS Foundation Trust and other local NHS providers. Together, agree what needs to happen to keep the NHS workforce well – especially frontline caregivers. Build this into providers' 2014/15 'improvement contract'
- Review how the NHS employers, North Lincolnshire Council and local schools supports staff with caring responsibilities; become exemplary
- Continue to apply commissioning approaches that involve front line staff. Ensure the results are fed back directly to front line staff: 'You said; we did'. Raise the profile of the CCG experience led approach to commissioning – explaining it is based on listening to and co designing care with front line staff and people who use services. Ensure staff feel they have permission to participate from their employer – including being freed up from their caring duties to participate in co design events
- Run more engagement and co-design events on site in NHS premises so people can contribute as part of their working day
- Discuss with NLAG and other providers how they are going to respond to the feedback in this work and systematises ways of working that empower front line teams and harness their enthusiasm and energy to improve things. Build actions agreed into providers' 2014/15 'improvement contracts'
- Agree set of outcome measures with Trust management around how they appreciate, recognise and value the great work front line teams already do. Measure the change in staff morale and feelings of empowerment – with a particular focus on people feeling respected trusted and in control of quality and improvement as part of performance management.



- Monitor levels of wellness amongst the NHS workforce
- Consider investing in further diagnostic co-design work with NLAG community teams and RDaSH mental health teams - and with workforce in general practice (and other primary care providers) - to find out how those who deliver front line care and those who run these organisations feel about keeping well
- Specify that providers put in place peer support for front line teams – especially those involved with delivering care directly to people and families - including support around dealing with grief and traumatic experiences
- Explore how opportunities to exercise can be offered during the working day e.g. organised lunchtime walking clubs, which would also provide an opportunity to talk, get peer support and provide the opportunity to get to know people in other teams
- Explore further and work with front line care givers and GP teams to find out why people who work in NHS services appear to have a less supportive relationship with their GP than the community more generally – and what can be done to improve this; co design an improvement plan with GPs and front line staff
- Explore with NLAG and other providers how primary care services can be made more accessible to the NHS workforce e.g. GP clinics held in Scunthorpe Hospital for staff - and how staff can get easy access to other health screening initiatives without needing to take time off work
- Raise awareness amongst staff of the need to ***'keep well to care'*** and that an investment in their own health is really an investment in the health of the people they love and the people they care for at work. This is also an important message for family carers.

Person centred outcome measures

The local community fed back to the CCG during this work that it currently measuring the wrong outcomes. They said that the outcomes the CCG are using are too clinical. In order to drive forward a new health and well-being approach, the community said the CCG needed to focus on measuring a set of more experiential outcomes. This work has identified what some of those outcomes might be. This is an initial set of suggestions. They are:

Care (system) experience

- Improved experience of transitions (as per emotional maps)
- Improved experience of crisis in care (as per emotional maps)
- Short or no waiting times for responsive services that support 'mobility maintenance'
- Performance management of services around how they contribute to the person doing what matters to them (fulfilling purpose)
- Integration and systematic access to peer support
- Increased access GP appointments; easier booking systems – including on line
- Drop in advice at Children's Centres (or other easily accessible community venues) for parents looking for reassurance around urgent health issues

Person's experience

- I feel listened to, supported, respected, understood and treated as a person
- I feel confident and able to manage my condition and keep well myself
- When I need reassurance about health issues, there is someone I can talk to easily

- I have a 'safe person' **whom I choose** to be my contact to connect with about keeping well (not always or necessarily a health care professional). He or she helps me and my family to do the things that keep us well and independent and to stay on track when things are in transition
- I have easy access to peer support from 'people like me' with lived experience – if I want it. I learn from my peers. I am coping and managing my condition and keeping well as a result
- My caregivers recognise the importance of and support my emotional well being
- My caregivers understand what matters in my life (purpose) and work with me so I can do the things that matter
- I feel able to contribute my 'gifts' and care for others in of need support and help
- I feel supported by my employer to keep well
- My caregivers support me to stay connected with my friends and family
- I have the life skills I need to be a good parent, carer – to live independently

In addition to the above for carers:

- I feel supported by caregivers to keep well and cope with the challenges of caring for my loved one(s)
- I feel I am able to be an effective advocate for my loved one(s)
- I understand my loved one's condition and how to manage it
- As a carer I feel listened to, supported, respected, understood and treated as a person
- I feel supported by my employer to care for my loved one – especially in times of transition or crisis



In addition to the above for front line NHS staff:

- My employer provides opportunities for me to network with and get support from my colleagues
- I feel respected, appreciated and valued
- I feel involved in improving services and quality
- I feel listened to
- I have opportunities to exercise during the working day

There is still more work to be done to define the person centred outcomes that will help commissioners leading Healthy Lives, Healthy Futures to track progress towards a relationship based care model that keeps people well. It should be noted that the local community sent a very strong message that the NHS in general and CCGs in specific are placing too much emphasis on clinical outcome measures – and not enough on ‘experiential’ ones.

The community want to work with the Healthy Lives, Healthy Futures team to change this – and to get involved in monitoring progress and the changes as they happen. This energy is a big opportunity and asset for the Healthy Lives, Healthy Futures team to harness. Changing the balance around the outcomes to be measured will demonstrate commissioners have ‘big ears’; and want to work in truly collaborative partnership with the community.

The voluntary sector has agreed to work with the CCG to explore how local people could be trained up to undertake evaluation of services – and gather more real time feedback not only on how things are now and are improving – but also what else needs to change. By 2015, the local community want to see the CCG and local people have made good progress on this new approach, with new experience led outcome measures in place - and the CCG improving services in line with what people who use them say matters – systematically.



We would suggest an early action would be to build on this community commitment and for North Lincolnshire CCG to use its local use its local ELC practitioner team to run an Improvement Contract Co Design Event (Co Design 5 of the ELC™ Framework) with key providers (including NHS trusts, voluntary sector and GPs) to cement the Healthy Lives, Healthy Futures outcomes framework, building on the ideas in this report. To drive co-ordinated, relationship based care, the outcomes framework developed should be applied to all providers. This is exactly what ELC Co-Design 5 is designed to do.

More work also needs to be done to look at existing outcome measures and what new ones might need to be created to facilitate measurement of what matters – rather than what is easy to count. It may be necessary to pioneer new approaches locally – if none suitable exist.

List appendices

Appendix number	Content
1	Output 13 March event
2	Online questionnaire script
3	Description of emotional touch points
4	Families with preschool children
5	Families with school aged children
6	Families with children with disabilities
7	Care home residents and staff
8	Older people living independently
9	People in recovery from substance misuse
10	GP patients
11	Public sector employees
12	PATH write up
13	List of community building support organisations