West Yorkshire & Harrogate
Health and Care Partnership

Digitisation and Personalisation
engagement and consultation mapping

June 2019

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Summary

This report demonstrates how a number of organisations across West Yorkshire and Harrogate (WY&H) have started conversations at a local level regarding digitisation (digital technology) and personalisation (making care personal) and provides a baseline for any future engagement work needed at a local and WY&H level.

This mapping exercise captures insight gathered from engagement and consultation which has taken place over the past 3 years. This report is intended to:

- Provide information on work which has taken place or is underway to avoid duplication
- Highlight any gaps in activity across West Yorkshire and Harrogate
- Understand some of the emerging themes gathered from local people across West Yorkshire and Harrogate
- Ensure that future plans have a baseline of engagement intelligence to support the work.

Digitisation (digital technology)

The key emerging themes from all the information reviewed for digitisation are:

- Most people said they used technology such as a telephone, smartphones and the internet. The telephone is the most commonly used item of technology.

- Not everyone could access the internet at home – cost and fears of affordability, poor signal, and lack of equipment, confidence and understanding of how to use the equipment were cited as a barrier to accessing technology. Some people were worried about 'being left behind' as technology continues to develop.

- Most people are supportive of the use of technology - such as enabling people to have video appointments with their GP or health professional. Most people would consider user technology such as telecare/telehealth. Technology in a care home setting was not favoured as much as seeing a GP although care home staff were supportive but concerned about the reliability of internet connections. People could see the benefits of using technology, and how the use of it could help people to maintain their independence. However, there was cautious support from some people with the recognition of the ongoing importance of human contact. People also felt that more should be done to help people learn about the digital world and get support to access it.

- Overall people were supportive of their health care records being shared with other professionals. However, there were some concerns about information being secure and confidentiality requirements for different levels of professionals. There were also some concerns around sharing data with local council staff i.e. care workers, social workers and not having sufficient medical training to understand health records.

- Concerns if healthcare professionals make decisions based on information that is no longer accurate and fears that something might go wrong with technology that might lead to incorrect diagnosis and prescriptions. People were also generally happy for

anonymous information being used to help improve services and also identify people at risk of disease.

- GPs were the most trusted professionals in using personal data - GPs are trusted more than the NHS in general. Generally, people were also happy for their information to be used to help the NHS and local councils to plan services.

Personalisation (making care personal)

The key emerging themes from all the information reviewed for personalisation are:

- Self-care needs to be supported. Some people are worried they won't have the right information or communication to support this. Confidence, skills, knowledge and training were needed (all free of charge) and people want systems to change to ensure they are given the support they need to navigate the system.

- Overall people were willing to be involved in their own health management. People said to make an informed decision they needed time and understanding of all options available, lots of information and clear communication.

- Clinicians need to be more' person-centered' and have an understanding of the person's lifestyle to decide the most appropriate treatment and also to be given the correct information.

- Online support was the preferred option for information. People said they would access support, help and get advice and information from the internet. More information is needed on safe sites that offer clear guidance. Not everyone has access to online information or the capability to obtain online support. This should be in addition to and not instead of personal contact.

- Peoples understanding of self-care was keeping fit and healthy - taking responsibility of your own health and wellbeing. Some described self-care as only looking after yourself when you're ill. People want an emphasis on the local support available including information from clinicians and more social prescribing.

- Barriers to self-care including lack of knowledge, time, depression and personal issues such as caring responsibilities, money worries, confidence and lifestyle were all barriers. Over-reliance on the NHS to pick up ill health was also mentioned. People want the information they need and face to face contact to navigate services.

- Specific support for mental health, including people to talk to, where the person feels listened to and heard. Not feeling isolated with more awareness of the support available in local areas, flexible appointments and environments that empower and involve people.

- Specific support for people with cancer such as more access to support at the end of treatment such as the right information at the right time and tailored to meet the needs of the patient, online support and peer support groups. People also wanted support to ensure individuals have the confidence and skills to manage their condition themselves.

Section 1: Introduction to the report

1. Purpose of the report

The purpose of this report is to provide information on any engagement and consultation which has taken place over the past 3 years on digitisation (digital technology) and personalisation (making care personal). This mapping exercise captures any intelligence collected from engagement and consultation activities carried out across West Yorkshire and Harrogate during the period April 2016 to June 2019 (Right Care, Right Time, Right Place composite report refers to reports dating back to March 2013 up to August 2018).

The report will support commissioners to:
- Provide information on work which has already taken place or is underway to avoid duplication
- Highlight any gaps in activity across West Yorkshire and Harrogate
- Understand some of the emerging views gathered from local people across West Yorkshire and Harrogate
- Ensure that any future plans have a baseline of engagement intelligence to support the work

In addition, the report will be a working document which is added to as projects progress.

The intelligence collected will ensure we meet our legal requirements and ensure we:
- Consider the views of patients and the public as part of service redesign; and
- Ensure the feedback is considered in the development of any future options to change the way a current service is provided or delivered
- Highlight patient and public priorities and ensure these priorities are in line with current thinking and ensure commissioners can consider all public views

2. Background

West Yorkshire and Harrogate Health and Care partnership is not a new organisation, but a new way of working to meet the diverse needs of our citizens and communities. NHS services have come together with local authorities, charities and community groups to agree on how we can improve people's health and improve the quality of their health and care services.
Our approach to collaboration begins in each of our six local places (Bradford District and Craven, Calderdale, Harrogate, Kirklees, Leeds and Wakefield). These places are the primary units for partnerships between NHS services, local authorities, charities and community groups, which work together to agree how to improve people's health and improve the quality of their health and care services.

Within each local authority, place are local neighbourhoods in which GP practices work together with community and social care services, to offer integrated health and care services for populations of 30-50,000 people. These integrated neighbourhood services focus on preventing ill health, supporting people to stay well, and providing them with high-quality care and treatment when they need it. Neighbourhood services sit within each of our six local places (Bradford District and Craven, Calderdale, Harrogate, Kirklees, Leeds and Wakefield).

The focus for these partnerships is moving increasingly away from simply treating ill health to preventing it, and to tackling the wider determinants of health, such as housing, employment, social inclusion and the physical environment.

These place-based partnerships, overseen by Health and Wellbeing Boards, are key to achieving the ambitious improvements we want to see. However, we have recognised that there are also clear benefits in working together across a wider footprint and that local plans need to be complemented with a common vision and shared plan for West Yorkshire and Harrogate as a whole. We apply three tests to determine when to work at this level:

- To achieve a critical mass beyond the local population level to achieve the best outcomes;
- To share best practice and reduce variation; and
- To achieve better outcomes for people overall by tackling 'wicked issues' (i.e., complex, intractable problems).

In February 2018 we published 'Our Next Steps to Better Health and Care for Everyone' you can read it here. We will be refreshing this plan in the autumn to reflect any alignment needed for the development of our five-year plan as set out in the NHS Long Term Plan here.

Below is a map of all the organisations involved in the West Yorkshire and Harrogate Health and Care Partnership.
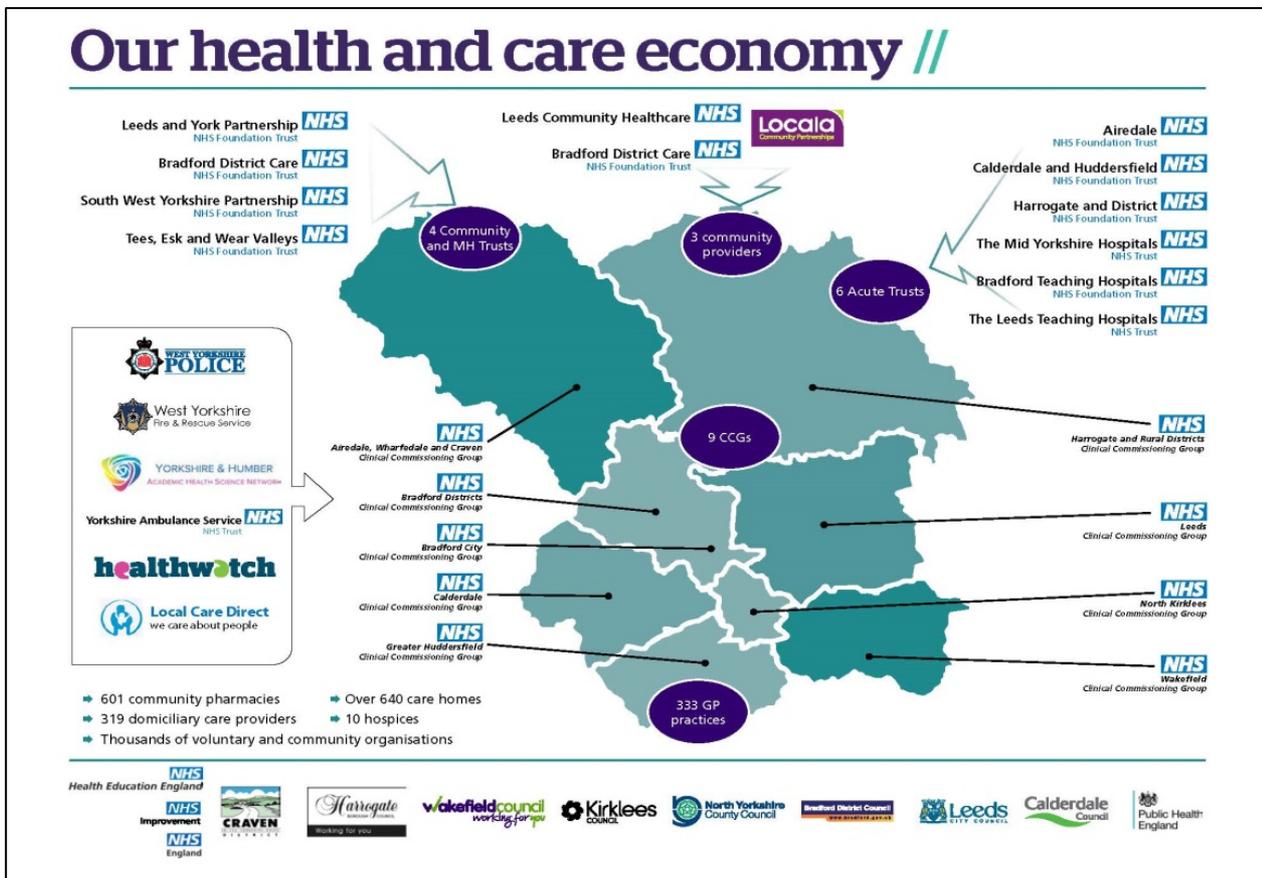
3. Process

The documents in this report were sourced via requests to the West Yorkshire and Harrogate Health and Care Partnership work stream leads, engagement leads across CCGs, Healthwatch and provider organisations, and a review of documents held on websites of all key organisations.

Each document was reviewed, and the key themes and details were written up into an evidence summary. The majority of the work that was sent had already been thematically analysed, and in those cases, the themes were copied. Some of the engagement and consultation reports that were reviewed had also been analysed to establish if there was any variation in the views expressed by people from protected groups. Any specific themes raised by protected groups are also included within this document.

After summarising all of the documents, the key themes from those documents were reviewed and a list of the key themes for each of the workstreams was created. Consideration was given to how many pieces of work that theme had been mentioned in, how many people had taken part in the engagement activity that mentioned the theme, and how much discussion there had been around that theme by the people who had been involved in that engagement.

4. Use of existing data

For this updated report, a review has taken place of all relevant engagement and consultation that has taken place between April 2016 and June 2019.

The mapping consists of **nine documents** which have been reviewed for this report. Some were produced by Clinical Commissioning Groups (CCGs), Voluntary and Community Sector (VCS) and Local Authorities.

See Appendix A for a list of the documents reviewed.

5. Our responsibilities, including legal requirements

Engaging people is not just about fulfilling a statutory duty or ticking boxes, it is about understanding and valuing the benefits of listening to patients and the public in the commissioning process.

By involving local people we want to give them a say in how services are planned, commissioned, delivered and reviewed. We recognise it is important who we involve through engagement activity. Individuals and groups play different roles and there need to be engagement opportunities for both.

A West Yorkshire and Harrogate Communications and Engagement Strategy underpins the principles by which the engagement and consultation will operate, and highlights the commitment to good practice in delivery. Engaging people who use health and social care services and other stakeholders in planning services is vital to ensure services meet the needs of local communities. It is also a legal requirement that patients and the public are not

only consulted about any proposed changes to services but have been actively involved in developing the proposals.

5.1. Legal requirements

There are a number of requirements that must be met when discussions are being made about the development of services, particularly if any of these will impact on the way these services can be accessed by patients. Such requirements include the Health and Social Care Act 2012 and the NHS Constitution.

Health and Social Care Act 2012, sets out the Government's long-term plans for the future of the NHS. It is built on the key principles of the NHS - a comprehensive service, available to all, free at the point of use, based on need, not ability to pay. It sets out how the NHS will:

- put patients at the heart of everything it does, 'no decision about me, without me'
- focus on improving those things that really matter to patients
- empower and liberate clinicians to innovate, with the freedom to focus on improving healthcare services

It makes provision for CCGs to establish appropriate collaborative arrangements with other CCGs, local authorities and other partners, and it also places a specific duty on CCGs to ensure that health services are provided in a way which promotes the NHS Constitution - and to promote awareness of the NHS Constitution.

Specifically, CCGs must involve and consult patients and the public:

- in their planning of commissioning arrangements
- in the development and consideration of proposals for changes in the commissioning arrangements, where the implementation of the proposals would have an impact on the manner in which the services are delivered to the individuals or the range of health services available to them, and
- in decisions affecting the operation of the commissioning arrangements where the implementation of the decisions would (if made) have such an impact

The Act also updates Section 244 of the consolidated NHS Act 2006 which requires NHS organisations to consult relevant Overview and Scrutiny Committees on any proposals for a substantial development of the health service in the area of the local authority, or a substantial variation in the provision of services.

The duties to involve and consult were reinforced by the NHS Constitution which stated: 'You have the right to be involved directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services'.

The Gunning Principles set out the legal context for the consultation process. Public bodies need to ensure that they are working within this framework and can withstand any scrutiny on each of the principles set out below.

- Consultation should occur when proposals are at a formative stage
- Consultations should give sufficient reasons for any proposal to permit intelligent consideration
- Consultations should allow adequate time for consideration and response
- Consultation responses must be conscientiously taken into account - there must be clear evidence that the decision maker has considered the consultation responses, or a summary of them, before taking its decision

The Equality Act 2010 unifies and extends previous equality legislation. Nine characteristics are protected by the Act, age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation.

Section 149 of the Equality Act 2010 states that all public authorities must have due regard to the need to a) eliminate discrimination, harassment and victimisation, b) advance 'Equality of Opportunity', and c) foster good relations.

To help support organisations to meet these duties a set of principles have been detailed in case law. These are called the Brown Principles;

- The organisation must be aware of their duty.
- Due regard is fulfilled before and at the time any change is considered as well as at the time a decision is taken. Due regard involves a conscious approach and state of mind.
- The duty cannot be satisfied by justifying a decision after it has been taken.
- The duty must be exercised in substance, with rigour and with an open mind in such a way that it influences the final decision.
- The duty is a non-delegable one.
- The duty is a continuing one.

An Equality Impact Assessment (EQIA) will need to be undertaken on any proposals for changes to services that are developed through the programme, in order to understand any potential impact on protected groups and ensure equality of opportunity. Engagement must span all protected groups and other groups, and care should be taken to ensure that seldom-heard interests are engaged with and supported to participate, where necessary.

Secretary of State's key tests
Any service change proposals are expected to comply with the Department of Health's four tests for service change. These are:

1) Strong public and patient engagement;
2) Consistency with current and prospective need for patient choice;
3) A clear clinical evidence base; and
4) Support from proposals from clinical commissioners

For significant service changes, NHS England operates an assurance process whereby they provide support and guidance to commissioners so that they can demonstrate compliance with the four tests and other best practice checks. The assurance process concludes with an assurance checkpoint at which time NHS England provides a recommendation regarding whether the tests have been met.

6. Engagement and consultation activity at a glance

In order to deliver the priority areas in West Yorkshire and Harrogate, it is essential that partnership networks work together to understand the views of local populations.
A number of organisations across West Yorkshire and Harrogate have already started to host conversations about the priority areas at a local level, this information needs to be considered and used so we are not over consulting our local populations. Using the mapping exercise included in this section it is clear to see that there is already a wealth of information and intelligence that can be used to support any future commissioning decisions. Where there are gaps in this information we can progress to have further conversations based on what we already know. The information in this document can also be cross-referenced with the priorities in the NHS Long Term Plan to support identification if any gaps. This means that any future service provision uses what we already have, prevents duplication of existing conversations and ultimately has the public at the centre of everything we do. In addition, work done regionally should not confuse the public who may have given their views at a local level. The communications supporting any further engagement and consultation activity needs to be managed with this mapping in mind.
The table below sets out the conversations already hosted across West Yorkshire and Harrogate on digitisation and personalisation.

For the purpose of the mapping we wanted to know;
- Any engagement completed which would provide intelligence;
- Any formal consultation which has ensured a service is in the process of being changed based on the engagement activity.

Each of the identified priority areas is then looked at in more depth drawing on the information from each local area. This is based on what we already know but may not be exhaustive.

1.1 West Yorkshire and Harrogate engagement and consultation activity at a glance on Digitisation and Personalisation

(E= Engagement, C = Consultation)

Key themes	Digitisation	Personalisation	Key reports
Bradford District and Craven	E	E	Healthwatch follow up appointments, Joined up Yorkshire, Frailty and technology
Calderdale	E	E	Healthwatch follow up appointments, Joined up Yorkshire, Care Closer to Home Calderdale, Right Care Right Time Right Place
Harrogate and Rural District	E	E	Healthwatch follow up appointments Joined up Yorkshire, My Health My Tech
Kirklees	E	E	Healthwatch follow up appointments, Joined up Yorkshire, Right Care Right Time Right Place, Kirklees Operational Plan and NHS Long Term Plan Event
Leeds	E	E	Healthwatch follow up appointments, Joined up Yorkshire, Coproducing personalised care; working with people
Wakefield	E	E	Healthwatch follow up appointments, Joined up Yorkshire, Connecting Care

Section 2: Findings from engagement on Digitisation (Digital Technology) and Personalisation (Making Care Personal)

1. Digitisation
The key emerging themes from all the information reviewed for digitisation are:

- **Telephones, smartphones and the internet -** From those surveyed most people said they used technology such as a telephone, smartphones and the internet. The telephone is the most commonly used item of technology.

- **Not everyone could access the internet at home –** cost and fears of affordability, poor signal, lack of equipment, confidence and understanding of how to use the equipment were all cited as a barrier to accessing technology. Some people were worried about 'being left behind' as technology continues to develop.

- **Most people are supportive of the use of technology -** such as enabling patients to have video appointments with their GP or health professional. Most people would consider user technology such as telecare/telehealth. Technology in a care home setting was not favoured as much as seeing a GP although care home staff were supportive but concerned about the reliability of internet connections. People could see the benefits of using technology and how the use of it could help people to maintain their independence. However, there was cautious support from some people with the recognition of the ongoing importance of human contact. People also felt that more should be done to help people learn about the digital world and get support to access it.

- **Sharing health care records -** Overall people were supportive of their health care records being shared with other professionals. However, there were some concerns about information being secure and confidentiality requirements for different levels of professionals. There were also some concerns around sharing data with local council staff i.e. care workers, social workers and not having sufficient medical training to understand health records.

- **Information stored on health care records -** Concerns if healthcare professionals make decisions based on information that is no longer accurate and fears that something might go wrong with technology that might lead to incorrect diagnosis and prescriptions. People were also generally happy for anonymous information being used to help improve services and also identify people at risk of disease.

- **GPs were the most trusted professionals in using personal data** - GPs are trusted more than the NHS in general. Generally, people were also happy for their information to be used to help the NHS and local councils to plan services.

1.1   Kirklees Operational and NHS Long Term Plan event

Findings from Digital Technology

People were asked how they currently use digital technology they have now. People said that they use telephones, smartphones, tablets and computers. People also said how they like to use each of these items to support Healthcare.

Telephone: The majority of people use the telephone to get a GP appointment in the morning, but a lot do not like the fact they have to constantly ring until they get through. Some people said they prefer the telephone as this means they can talk to someone and they like the GP telephone consultations.

Smartphone: Smartphones are used to access social media such as FACEBOOK or to use APPS. The Apps described as being used were:
- Exercise apps
- Drink monitoring app
- Weight tracker app
- Calorie counter app
- Online appointments
- To use google for symptoms, advice
- Hospital sends text messages for appointments

A few people said their device was too small to use for more advice, and they would probably use it in conjunction with other support but not as the sole device. The device is too small to use for items that required a lot of text.

Tablets: Tablets were much easier to use as the screen size lends itself to reading information. People were already using tablets and would be happy to use this technology to SKYPE people and to access personal medical records. However, there were a number of issues which included:
- Not logging on for appointments often enough can mean people who do not use at least every 3 months will be locked out.
- A preference for face to face communication but ok to use if a backup system is in place
- Free Wi-Fi needs to be available to support use.

Computers: Computers supported more opportunities to gather information and to do research. However, some people were concerned about the legitimacy of the website and the information they may receive. People used computers already to gather information on;

- Long term conditions particularly charity websites for rare conditions
- Symptoms
- Medication - ordering prescriptions
- Referral pathways and NICE guidance
- Peer support groups (Facebook)
- To research healthcare
- Make appointments online: which enables a choice of when and who you see which is very good.
- Spreadsheet to monitor blood pressure, weight and exercise useful when seeing GP
- Monitor blood pressure, check test results and book appointments.

Telehealthcare: Not many people attending at heard of or used this technology. For those who had they thought the idea was sensible and gave peace of mind. For some who had, they found the use of telehealthcare successful but expensive. However most felt that this needed to be combined with face to face contact.

Key themes, from all this work the conclusions are that those attending liked the following:
- Prescriptions online: people found this service easy to use
- Online appointments
- Blood pressure monitoring results on a screen
- Using technology to ensure services are more efficient
- Good idea to have info available online and can be used in conjunction with pharmacy/ local services
- Some liked the idea of talking to a health care professional via SKYPE and felt it would fit in with their busy lives, reduce time off work and the need to travel and for people with complex needs who struggle with or do not like clinical settings
- Online conversations could involve more than one health care professional to support complex health needs and integrated working

From those attending the key areas for development and concern are listed below, people said:
- People with sight loss need support, help and training to use technology and there we need to link to support groups who can help with this
- Find telephone consultation useful and it is an efficient use of time. Not sure about moving on to Skype/ FaceTime arrangement.
- Some people do not have the confidence to use a smartphone
- Most people were happy to use technology but like the option to phone and speak to someone
- Health professionals need to know about community groups – what they are and what they can do. They can help with technology

- People were not sure how well it works with an urgent care issue and when you need to see someone
- APPS offer limited support for people with sight loss and the elderly including people with dementia and those who have a first language that is not English including deaf people
- Technology needs to be simplified to support everyone to use
- As much as technology is great, mental health patients can panic
- People worry about the legitimacy of advice on the internet
- Websites are daunting for some and for those who have grown up with visiting the GP they like the fact a GP touches and feels you which is more reassuring
- Using everything online could make you more isolated and sedentary than a visit to see someone
- People are worried about how secure information was and having conversations in settings that were not private
- Online appointments should cater for joined-up assessments too
- Technology can add more pressure on to a carer

1.2   My Health My Tech (North Yorkshire)

North Yorkshire County Council held a series of informal open door drop-in workshops in March 2019. A short survey was also developed to provide other ways for people to give their views.

A strategy called My Health My Tech is being developed which will provide a ten-year plan of how technology can be used to help people to live well, receive information, support and treatment when people need it and make choices about how their care services are provided.

An interim report has been developed to provide an overview of the intelligence collected to date to help inform the work of the strategy and highlight any emerging trends.

The main themes from the engagement to date are that there are similar themes emerging from the events and survey, with a general feeling of acceptance of the increased use of digital technology.

Key themes from the drop in events are below:
- An overarching theme of the three sessions was **'cautious support'**. Perhaps understandably for a group who had chosen to attend a workshop on technology, there was a reasonable level of understanding and enthusiasm for the potential role of technology in supporting people to stay healthy. Some people are already using technology in life-changing ways (see below) and were interested to hear about innovations for the future.

- The key 'caution' people raised was with regard to the **ongoing importance of human contact**. Many people could see a place for online consultation and contact and noted the benefits for patients (being able to choose their appointment times more flexible, not having to travel) and the overburdened health system. However many observed that online contact alone should not replace all face to face interaction. Some noted that this would not allow practitioners to observe some symptoms or conditions with their own eyes. ('*Online contact as an addition to face to face care would be more acceptable but not as sole means of communication'*). There was also concern about increasing social isolation, with some respondents believing that this would be one more reason for people to stay at home and not engage in the community as much.

- Several respondents raised concerns about **the poor availability and speed of internet access across North Yorkshire, especially in rural areas**.

- **The cost was also raised as an issue**, with fears that affordability of technology (including access to the internet) might preclude some people from accessing health services on an equitable basis with others in the community.

- People also raised the issue of needing to be 'tech-savvy' noting that whilst training is often made available for professionals, there would need to be **some level of training for the public** in the use of emerging technologies.

- Some people raised issues regarding the **need for trust in the systems**. These included a fear that something might go wrong with the technology that might lead to incorrect diagnoses and prescriptions. There were also concerns about **privacy** and sharing of personal medical information. Some people felt that wearable devices equated to an Orwellian 1984/'Big Brother' future which they were uncomfortable with.

Themes raised from the survey

Key themes for 'what is good about these ideas':
- Could improve accessibility for people with communication needs, including Deaf people – need to think about inclusivity
- Could improve access by reducing the need to travel; improving contact for people in rural communities
- Encourage self-management and resilience
- Better information-sharing
- Contact and help quicker and more responsive
- Could provide more individually tailored solutions for people
- Could help to support delivery/ reduce pressure on services and budgets that are already stretched

Key themes for 'what worries you about these ideas':
- Concern about rurality and poor broadband access
- Concern about proposals leading to poorer quality service, issues being missed if contact does not face to face
- Privacy and information security concerns; intrusive; not accurate
- Increased social isolation, loss of human contact
- Digital exclusion for those who lack technology skills, access to kit and broadband, cost
- Needs organisational resources, funding, skills to deliver

Key themes for 'practical things to consider':
- Think about practical aspects such as access to kit and internet, affordability
- Make sure everything is user-friendly – language, usability, appearance, accessibility, availability of support, quick repairs
- Ensure security and reassure people about this
- Support for people - training, buddies, peer support, community support, community hubs
- Consider individual's capacity/ability to cope with new digital tools; check/re-assess regularly
- Cost/benefit of digital solutions (including comments about remembering low-cost tech solutions e.g. dosette boxes as well as more sophisticated)
- Ensure kit actually works, does what it is supposed to do and is reliable
- Importance of health and social care integration

Key themes for 'anything else you would like to tell us':
- Link in with existing services that use digital technology eg Assistive Technology
- Remember to look at / make use of readily available everyday technology eg tablets
- Pilot new ideas
- Importance of human contact, digital technology should not supersede or reduce this
- Be honest about reasons for change
- Importance of individual approach

1.3   Joined up Yorkshire

In autumn 2018 The Yorkshire and Humber Care Record team commissioned this research to provide insight into people's beliefs about their health and care record being shared. This report presents the research findings and lists recommendations for the Yorkshire and Humber Care Record team.

The Yorkshire and Humber Care Record is an innovative programme that has the potential to produce a transformational change in healthcare in the region. Currently, patient data is not shared between the NHS and other organisations that play a role

in health and social care, such as care homes, social services, and private clinical care organisations.

The Yorkshire and Humber Care Record is being developed to address the problem of data sharing. It is a digital care record which enables clinical and care staff to access real-time health and care information across health and social care providers and between different systems. It brings together a core of information about patients who have used services provided by their GP, local hospitals, community healthcare, social services or mental health teams. This information is stored on a secure computer system and so can be accessed by different care providers regardless of the computer system they use.

The results show that people welcome greater sharing of health and care records, particularly by clinical staff for their direct care. They also recognise the benefits of the NHS and local councils analysing their anonymous health and care records to plan services and to better understand and treat diseases. There is clear support for the Yorkshire and Humber Care Record for:
• direct care;
• planning services;
• research for the public good;
• engaging people in their health management.

There have been changes since the previous Joined up Leeds research, with:
• more people aware of the value of personal data;
• more aware of the control they have over their data;
• and more concerns over the potential for security breaches.

The main themes raised were:
• The results show that there is strong support for the Yorkshire and Humber Care Record as people believe it will improve patient-centred care, improve continuity of care, improve communication between different health and care teams, improve the accuracy of diagnosis and prescribing, and generally lead to a more efficient and cost-effective service. However, they wanted access to be restricted to current and relevant information.

• The research shows that many people are unaware of the role that local councils play in providing and planning care services and believe that only the NHS has this responsibility. Because of this, many have concerns about why the local councils would need to access their health and care records. The Yorkshire and Humber Care Record team should, therefore, raise awareness of the role of local councils in direct care and in planning health and care services.

• Nearly all (95%) of the survey participants supported their data being used beyond their direct care, most commonly to plan services, to help people stay

healthy and for research into understanding, diagnosing and treating diseases. There was also support for using health and care records to intervene before people develop a health condition, which may include contacting people at risk in order to offer screening or healthcare advice and engaging them in managing their own health. Nevertheless, participants had concerns about data sharing, primarily their data being sold to third parties, or there being a data security breach. They were concerned that the NHS and local authorities use outdated IT systems, which places their information at risk. GDPR has made people more aware of the data that is collected about them and of the control they have over that data.

- The results show that people have the most trust in their GP practices, followed by the NHS in general, then banks or building societies, the local council and universities. Accordingly, they prefer any contact about future health risks and managing their health to come from their GP.

1.4   Frailty and technology focus group (Bradford)

In May 2018, Bradford CCGs worked with research colleagues to develop a proposal to be a 'test-bed site' to research new technologies which might support frail, older people to live independently at home. This research aims to help people play a more active role in their own care through the use of three smart devices combined with carer and professional involvement. Together they remotely monitor health, wellbeing and a person's living environment round the clock and in real time – learning a person's normal patterns and alerting carers, clinicians and care workers when something is wrong.

To support the application, and learn more about what people thought about using technology in this way NHS Bradford CCGs engagement team brought together a group of eight older people from different backgrounds to talk about this. Information was shared about the research proposal and then led an informal discussion about people's current experiences of technology and their thoughts about how they felt about using technology in the future.
The main themes raised from the session are below:

Overall, people in the discussion group described a lack of confidence in using technology. Although many of the older people were using smartphones or tablets to keep in touch with friends and family, they had worries about 'being left behind' as technology continues to develop.

When we described the digital solutions being explored in the test-bed application (smart home technology, shared digital care plans, and video consultations) people could see the benefits and how it could help people to maintain their independence. However, people wanted reassurance that digital solutions would be in addition to face to face care and support, rather than replacing human interactions.

People felt that if they couldn't use digital technology, they were potentially at a disadvantage. They felt that more should be done to help older people learn about the digital world and get support to access it.

There was a perception from people in the group that digital technology would be costly, both for the people using it and for the NHS.

1.5   Wakefield Connecting Care

Winter 2017 the connecting care partnership carried out an engagement piece of work which built previous engagement delivered by Healthwatch in December 2016. The self-care, telehealth and sharing care records engagement received over 240 survey responses, with face to face discussions taking place with over 90 people

Key themes regarding telehealth and sharing care records from the engagement are below;

- The majority (55.54%) of those who said no, felt that face to face contact was needed
- 78.03% of respondents said that they use a smartphone
- 95.38% said that they did use the internet
- 94.8% of respondents expected that their care record could be accessed by professionals when treating/supporting them
- 16.76% said that they did have some concern about sharing care records. However, 48.86% of these comments were positive, with some responders giving a proviso to allowing access but 10.22% did provide negative comments.

1.6   Healthwatch engagement on 'follow-up appointments'

In April 2017 Healthwatch engaged with local people in West Yorkshire and Harrogate on improvements to follow up appointments. Each year in the NHS 'follow-up' outpatient appointments mean patients are asked to return to the hospital to have their progress checked, to undergo tests, or to get test results. Whilst some of these appointments are clinically required, a large proportion could be done differently.

The engagement gathered views on delivering follow up appointments differently. This would mean replacing traditional face to face visits to the hospital with telephone calls, online services or an appointment at their GP practice. Healthwatch received feedback from 502 people. The findings relating to digital services are set out below:

- **94.6% (470)** of respondents agreed or strongly agreed that the NHS should offer people different ways to access a follow-up outpatient appointment, if appropriate for their condition.

- **87.4% (424)** of respondents agreed or strongly agreed that they would be happy to have a follow-up outpatient appointment **by telephone** rather than visit the hospital.
- **68.1% (323)** of respondents agreed or strongly agreed that they would be happy to have a follow-up appointment **by Skype or similar online tool** where the consultant is able to see them, rather than visit the hospital.
- **51.5% (243)** of respondents agreed or strongly agreed that they would be happy to have a follow-up outpatient appointment **by email** rather than visit the hospital.
- **39.2% (183)** of respondents agreed or strongly agreed that they would be happy to have a follow-up outpatient appointment **by text message** rather than visit the hospital.
- **12.4% (56)** of respondents agreed or strongly agreed that they would be happy to have a follow-up outpatient appointment **by fax or Typetalk** rather than visit the hospital.

The main themes raised were:
- Overall, people were very supportive of the proposal to be able to access their follow-up appointments in a different way, and most wanted these to be done face-to-face so they were able to ask questions. It was felt that text messages and email were only appropriate to use when letting people know that their test results were normal and no further tests or treatment was required.
Many commented on the positive benefits for them and the NHS.

The main benefits for patients were seen to be:
- A reduction in their travel time if they didn't have to travel to a hospital.
- Not having the stress and cost of parking at the hospital.
- Not having to sit for long periods of time in the hospital waiting room.
- Not having to take time off work or arrange childcare.
- The benefits for the NHS were seen to be the time and money that could be saved, that could be used to diagnose and treat other patients.
- A few people talked about how they had already been offered different ways to access their follow-up appointments and that it had worked well.
- Whilst people could see the benefits of being offered an alternative way of accessing a follow-up appointment they did express some concerns.

1.7   Right Care Right Time Right Place
As part of pre-consultation engagement on the programme Right Care, Right Time, Right Place, a number of specific audiences were engaged in the areas of Calderdale and Greater Huddersfield. In addition, we trawled through all the 'Patient Opinion' postings and Patient Advice and Liaison Service (PALS) queries received over the past two years. In total, we gathered 654 responses. We asked people to respond to a number of questions with one question relating directly to the use of technology. People who talked about the use of technology said that:

- 67% would use the mobile phone,
- 55% would prefer to use a computer or laptop
- 44% would try new technology
- 25% would if supported to use new technology,
- 23% would not use it or be able to access it

In addition, some of the **things we need to consider** when looking at the use of technology to support healthcare are:

- Poor Wi-Fi connection in a number of local areas
- People still want face to face contact as well as or instead of
- Expensive data usage for some with a mobile phone or no internet
- Lack of equipment or knowledge would need to be supported

Using technology:
- Use text reminders for appointments and for those requiring more support such as people with a learning disability, a phone call would be appreciated
- Emails can be difficult to read for some, a lot of people can't use or don't have access to a computer and need to be considered
- Training is needed to support the use of technology
- Language, translation and literacy are a barrier to using technology

1.8 Specific themes raised by protected groups

Some of the engagement and consultation that has taken place has been analysed to establish if there is any variation in the views expressed by people from protected groups. In addition to this, some pieces of work have focused on specific protected groups; these have included people with learning disabilities; young parents; BME communities; young white working-class communities; and emerging communities.

The key themes raised by protected groups were:

My Health My Tech (North Yorkshire)
A general observation regarding attendees was that there was not as significant a gap between generations as might be assumed. Many older people (60+) were familiar with new and emerging technologies and comfortable with tablets, smartphones and apps.

Wakefield Connecting Care report
While men and women in the sample are more likely to have phones than not, proportionately more women than men have them. All the younger people who responded used a smartphone, as expected this decreased with age.

When looking at smartphone use by disabled people compared to the full sample there was a considerable difference. 77.2% of the sample used smartphones,

compared to 21.9% of disabled people in the sample. Similarly, fewer carers used smartphones than the full sample, but more than disabled people, at 32.7%.
There is no significant difference between the sexes on the use of the internet. When analysing the results by age internet use is comprehensive with only minor differences by age, following the same downward trend as phone use.

However, when looking at disabled people and carers there is a striking difference with substantially fewer disabled people and carers having use of the internet proportionately.
The majority of people did not have concerns about sharing their care records until disabled people and carers were considered. Compared to 15% of the whole sample 31% of disabled people and 47% of cares had concerns about their care record being shared.

When the data was reviewed to consider telehealth there were very limited differences in whether different sexes and disabled and non-disabled people would consider telehealth as a way of self-caring. For carers and different age groups, there were some differences but they were not large.

In conclusion, there may need to be further engagement to understand more fully what protected groups feel about self-care, telehealth and shared care records. There are gaps for:
- Men
- Pregnancy and maternity
- Ethnicity and country of birth
- Age groups

The priorities for further learning and engagement would be to reach more diverse ethnic groups and younger people.

One of the main themes of the feedback was that the respondents suggested using schools and education to prepare people to care for themselves. It would be useful to test this with young people. Older people do need further enquiry to check how they feel about self-care, care records and telehealth and how they can be supported effectively as their reduced access to some of the tools in this survey sample would suggest that more work would be required to enable them to participate in any schemes effectively.

Joined up Yorkshire
A total of 1,031 people completed the survey. Most (86%) were completed online. More were female (63%) than male (37%), 10% reported having a disability, 18% reported having a long-standing illness or health condition and 11% a mental health condition. In terms of ethnicity, the survey respondents were mainly white (91%), which is higher than the 2011 census data for the region (86%). A third (33%) of survey respondents were based in Humber Coast and Vale, 21% were based in South Yorkshire and Bassetlaw and the remaining 46% were based in West

Yorkshire and Harrogate. The higher number of respondents from West Yorkshire and Harrogate is to be expected: this area comprises 47% of the 5.5 million people who live in Yorkshire and Humber. The remaining 2.9 million are split approximately equally between Humber

Figure 1: The percentage of respondents who believe different professionals should be able to access their health and care records (n=1031).
There were some age differences in the pattern of responses 1. People in the 25-64 age group were less likely to believe that practice nurses should be able to access records than those in the younger (<25) or older (>64) age groups (χ^2 (2) =25, p<0.001). People in the older age group were less likely to believe that social workers should be able to access their records than the other groups (χ^2 (2) = 24, p<0.001). There were no gender differences. People with a disability were more likely to believe that housing officers should be able to access their records (χ^2 (1) =15, p<0.001).

Very few age- and gender-related differences were seen in the results. Males were more likely than females to believe that people should be contacted if they are at risk of disease (χ^2 (2) = 11.8, p=0.003) whereas females were more likely to believe that data should be used to plan services (χ^2 (2) = 13.7, p=0.001). There were no differences based on disability.

1.9 West Yorkshire and Harrogate digitisation emerging themes engagement and consultation activity at a glance (E= Engagement, C = Consultation)

Key themes	Bradford District and Craven	Calderdale	Harrogate and Rural District	Kirklees	Leeds	Wakefield	Key areas covered
Telephones, smartphones and the internet		E		E		E	Most people said they used technology such as a telephone, smartphones and the internet. The telephone is the most commonly used item of technology
Not everyone could access the internet at home		E		E		E	Cost, poor signals and lack of equipment, confidence and understanding of how to use technology were all cited as a barrier to accessing technology. Some people were worried about 'being left behind' as technology continues to develop.
Most people are supportive of the use of technology		E	E	E		E	Enabling people to have video appointments with their GP or health professional. Most people would consider user technology such as telecare/telehealth. Technology in a care home setting was not favoured as much as seeing a GP although care home staff was supportive but concerned about the reliability of internet connections. Cautious support for the recognition of ongoing human contact. More should be done to help people learn about the digital world and get support to access it.
Sharing health care records	E	E	E	E	E	E	People were supportive of their health care records being shared with other professionals. However, there were some concerns about information being secure and confidentiality requirements for different levels of professionals.

							There were also some concerns around sharing data with local council staff i.e. care workers, social workers and not having sufficient medical training to understand health records.
Information stored on health care records	E	E	E	E	E	E	Concerns if healthcare professionals make decisions based on information that is no longer accurate. People were also generally happy for anonymous information being used to help improve services and also identify people at risk of disease.
GPs were the most trusted professionals in using personal data	E	E	E	E	E	E	GPs are trusted more than the NHS in general. Generally, people were also happy for their information to be used to help the NHS and local councils to plan services.

2. Personalisation (Making Care Personal)

The key emerging themes from all the information reviewed for personalisation are:

People said that for personal care to work; services need to:
- Listen to me, I know my body
- Explain my medication
- Make time to listen and understand
- Treat me as an individual
- Make things easier to navigate, simplify things
- Give carers a break and include them
- Help people get the services they need
- Jointly discuss and co-produce together
- Continuity of care means seeing the same person

- **Self-care needs to be supported** – some people are worried they won't have the right information or communication to support this. Confidence, skills, knowledge and training were needed (all free of charge) and people want systems to change to ensure they are given the support they need to navigate the system.

- **Overall people were willing to be involved in their own health management** - People said to make an informed decision they needed time and understanding of all options available, lots of information and clear communication.

- **Clinicians need to be more' person-centred'** – have an understanding of the person's lifestyle to decide the most appropriate treatment and also to be given the correct information.

- **Online support was the preferred option for information** – those surveyed said they would access support, help and get advice and information from the internet. More information is needed on safe sites that offer clear guidance. Not everyone has access to online information or the capability to obtain online support and this should be in addition to and not instead of personal contact.

- **Peoples understanding of self-care was keeping fit and healthy** - Taking responsibility of your own health and wellbeing. Some described self-care as only looking after yourself when you're ill. People want an emphasis on the local support available including information from clinicians and more social prescribing.

- **Barriers to self-care -** Lack of knowledge, time, depression and personal issues such as caring responsibilities, money worries, confidence and lifestyle were all barriers. Over-reliance on the NHS to pick up ill health were also mentioned. People want the information they need and face to face contact to navigate services.

- **Specific support for mental health** - People to talk to, where the person feels listened to and heard. Not feeling isolated with more awareness of the support available in local areas, flexible appointments and environments that empower and involve people.

- **Specific support for people with cancer** - More access to support at the end of treatment such as the right information at the right time and tailored to meet the needs of the patient, online support and peer support groups. People also wanted support to ensure individuals have the confidence and skills to manage their condition themselves.

2.1 Kirklees Operational and NHS Long Term Plan event

Findings from 'personalised care conversation'

We asked people to tell us what personalised care means to them. People talked about what personal care means and provided the key messages are:

- Listen to me, I know my body
- Explain my medication
- Make time to listen and understand
- Treat me as an individual
- Make things easier to navigate, simplify things
- Give carers a break and include them
- Help people get the services they need
- Jointly discuss and co-produce together
- Continuity of care means seeing the same person

We asked people to tell us the <u>three</u> most important things about the care they receive. People said:

- Being listened to and people having the time to talk
- Being able to speak to the doctor/ person you want to talk to (consistency)
- Having proper, timely feedback
- Co-ordinating care across different fields
    - need consistency
    - not repeating your story
- Signposting for all services. Simple information and clear communication including social prescribing in GPs and connecting to community facilities
- Links to a range of health and social care professionals
- Access to digital as one option – not the sole option
- Valuing that the patient knows what they need so you do not have to prove when you need treatment
- Parity of esteem between patient and clinician
- Consistency in care
    - seeing the same person who knows your story
    - everything should be on a computer

o GPs should have time to read this but don't always

We then asked what support people would need to make care more personal, people said

- Key person for people with complex needs in GP settings
  o particularly for people with learning disabilities (autism) (busy waiting rooms can be a challenge)
  o slow times to not sit in a busy waiting room
- Digital technology and web-based links to local services
- Getting feedback on websites to help with navigation including how easy/ difficult they are to use
- Learning from other care navigators
- Impact of other life events and caring should be considered in healthcare consultation – would help with prevention
- To not forget we are "lay people", need to talk to people on that level.
- Tell us what we need to know, an example given was "paying for dental appointments" when the person did not know they had to
- Make sure people go to the right place with the right equipment for treatment
- Listen to patients as they do know what they need and then signpost to appropriate people
- Single point of access for mental health
- Early intervention is not a common practice but it should be as people are left too long
- Centralised clinics to meet needs, particularly if people are older, have complex needs to make it easy to navigate systems

We then asked what improvements should we make to the current system? People said:

- Improved communication and information from the professionals you see that provide a coordinated view of the service which is joined up
- Manage appointments so you can do more than one thing at each appointment and see more than one person
- Sharing information i.e. single care plan so you do not have to repeat yourself
- Speak to people in the right way, ask the right questions so you get the information you need
- Reduce consultant letters as they are a waste of resource when you need an immediate solution. More information about a referral including what to expect
- Timely appointment times. Time constraints leave patient/ carer unsure of what is going on
- Practices are often not informed on who they can refer to this needs improving
- Involve people as esteem can be impacted if a clinician does not involve a patient

- Clinicians' limited understanding of multi-sensory issues means that rooms/ environments are not always suitable. Rooms need to be comfortable particularly for a child who wants to move around
- Young people mental health services are still really poor and practitioners have limited experience of ADHD, autism, learning difficulties so services need to look at matching patient to clinician
- Not much available to support young people to build skills to support a transition
- Need to qualify skills of staff to create specialist understanding and staff need to be tactful in delivering messages in the right way by being sensitive and compassionate
- Need to support people so they don't slip through the gap and clinicians need to have an awareness of wider social needs
- Adjust systems to support people to attend appointments particularly carers and people who have a mental health problem
- More opportunities to give carers a break, there is not enough respite available. Involve carers and make sure their views are sought
- Care homes need monitoring to make sure people get the care they need
- Provide places so people can get the information themselves to look after themselves, the more information the better
- Getting the right advice first time by ensuring more conversation with GP about what I need to have done
- More information and support on medication as drugs and medication is a big area

2.2 Coproducing Personalised Care; working with people

In 2014, Leeds held a workshop that specifically focused on this topic. And through their wider engagement and consultation on maternity services, all areas had collated feedback on personalised care and choice.

The main themes raised were:
- Women want to be offered the choice of where and how they give birth. To support them in this they need more information and support before pregnancy to ensure the right choices for birth are made, this should include support for dads.
- The need for better communication from staff about choices, what to expect from each birthing option and someone to explain things more clearly if needed.
- Most women use advice from professionals and family or past experience to inform their choice of birthplace;
- Information and access to alternative therapies such as hyno-birthing, acupuncture and other alternative pain relief.
- More support for first-time parents, including longer conversations about birthing options and what to expect, more appointments and earlier access to a midwife.

- Staff to listen to patients and respect any decisions – the mother knows what she needs in most cases – this included choices about breastfeeding and pain relief.
- To provide support to manage a long term condition during pregnancy and ensure there is holistic support for the whole person.
- Examinations, tests, scans and ultrasounds available in the local community i.e. GP practice, particularly for those who have concerns during pregnancy.
- Better access to midwives, including more available appointments, improved telephone contact and longer more flexible appointment times.
- Improved services on a weekend and evening including outpatient appointments. Contact numbers for out of hours support and advice and local drop-in clinics.
- Not feeling rushed when using services and being in a calm and relaxed environment with staff that are not stressed or rushing.
- All pregnant women should be told about antenatal classes by a midwife, this didn't always happen.
- Travel, transport and costs are a concern for some women – particularly those in outlying areas who may be on low incomes with young families.

2.3   Joined up Yorkshire

In autumn 2018 The Yorkshire and Humber Care Record team commissioned this research to provide insight into people's beliefs about their health and care record being shared. This report presents the research findings and lists recommendations for the Yorkshire and Humber Care Record team.

The Yorkshire and Humber Care Record is an innovative programme that has the potential to produce a transformational change in healthcare in the region. Currently, patient data is not shared between the NHS and other organisations that play a role in health and social care, such as care homes, social services, and private clinical care organisations.

The Yorkshire and Humber Care Record is being developed to address the problem of data sharing. It is a digital care record which enables clinical and care staff to access real-time health and care information across health and social care providers and between different systems. It brings together a core of information about patients who have used services provided by their GP, local hospitals, community healthcare, social services or mental health teams. This information is stored on a secure computer system and so can be accessed by different care providers regardless of the computer system they use.

The results show that people welcome greater sharing of health and care records, particularly by clinical staff for their direct care. They also recognise the benefits of the NHS and local councils analysing their anonymous health and care records to plan services and to better understand and treat diseases. There is clear support for the Yorkshire and Humber Care Record for:
- direct care;

- planning services;
- research for the public good;
- engaging people in their health management.

There have been changes since the previous Joined Up Leeds research, with:
- more people aware of the value of personal data;
- more aware of the control they have over their data;
- and more concerns over the potential for security breaches.

The main themes raised were;

- The results show that there is strong support for the Yorkshire and Humber Care Record as people believe it will improve patient-centred care, improve continuity of care, improve communication between different health and care teams, improve the accuracy of diagnosis and prescribing, and generally lead to a more efficient and cost-effective service. However, they wanted access to be restricted to current and relevant information.

- The research shows that many people are unaware of the role that local councils play in providing and planning care services and believe that only the NHS has this responsibility. Because of this, many have concerns about why the local councils would need to access their health and care records. The Yorkshire and Humber Care Record team should, therefore, raise awareness of the role of local councils in direct care and in planning health and care services.

- Nearly all (95%) of the survey participants supported their data being used beyond their direct care, most commonly to plan services, to help people stay healthy and for research into understanding, diagnosing and treating diseases. There was also support for using health and care records to intervene before people develop a health condition, which may include contacting people at risk in order to offer screening or healthcare advice and engaging them in managing their own health. Nevertheless, participants had concerns about data sharing, primarily their data being sold to third parties, or there being a data security breach. They were concerned that the NHS and local authorities use outdated IT systems, which places their information at risk. GDPR has made people more aware of the data that is collected about them and of the control they have over that data.

- The results show that people have the most trust in their GP practices, followed by the NHS in general, then banks or building societies, the local council and universities. Accordingly, they prefer any contact about future health risks and managing their health to come from their GP.

2.4   Wakefield Connecting Care

Winter 2017 the connecting care partnership carried out an engagement piece of work which built previous engagement delivered by Healthwatch in December 2016. The self-care, telehealth and sharing care records engagement received over 240 survey responses, with face to face discussions taking place with over 90 people.

Key themes regarding self-care from the engagement are below;

- People understood self-care to mean keeping well by healthy eating, exercise, taking responsibility for your own care including medication
- There was a feeling that lack of knowledge, lack of time and illness/depression might be barriers to self-care
- The main ways that people felt the NHS could help with self-care were by giving information and educating people (including professionals)
- There were varying responses to how people felt we could build people's confidence, skills and knowledge but communication and giving information (including social media and apps) and running courses and sessions were the top two themes
- People would mainly access support online, via voluntary and community groups or through Primary Care services.
- When thinking about mental wellbeing many people were not sure what support would help. However, many people stated that talking, being listened to and having help at work and not being isolated would help
- Many people (20.94%) were not aware of what mental wellbeing support was available in their area. However, almost 80% were able to name some support

Almost 70% of respondents said they would consider using telehealth

2.5   Care Closer to Home Calderdale

Calderdale Clinical Commissioning Group spoke with representatives from patient reference groups at the network meeting Calderdale Health Forum and groups of service users with long term conditions. In total just under 100 people were asked to describe supported self-care.

Key themes:
- Importance of providing the information, advice, support and guidance that allows people to self-care, particularly for those with long term conditions and for those who are newly diagnosed.
  - *'There is loads of rubbish to sift through, so many myths and variable opinions and advice. I get told different things about sugar levels by different health professionals'*
  - The majority of people reported that following a diagnosis of their long term condition, they are left to their own devices in terms of managing their illness.

Health professionals assume that patients understand the illness/condition diagnosed.

- One participant reported that despite undergoing major surgery for pancreatic cancer and subsequent diagnosis of diabetes, she was not informed of what support strategies were in place or services she could access to help her illness. She was not taught how to do sugar level testing, nor had the knowledge of what testing kits to use. She strongly felt that she had to do a great deal of independent learning.
- *'Need to know where to go. Still uncertain if it's 111, 999, the GP. Who do you call? Where do you go?'*

- Improving communication between different organisations to ensure services are seamless.
  - Poor communication between organisations/staff can mean that people are not assessed and treated holistically.

- Difficulties with managing and getting appropriate medication from pharmacies and hospitals.
  - Pharmacies don't always hold enough or any stock of medication needed and there are supplier/manufacturer problems.
  - As medication is vital in the management of many conditions, sometimes patients share it or give it to other patients because of availability issues. These discrepancies have to be explained to Doctors who don't seem to understand this need.
  - Sometimes a hospital prescription is offered but not always; this need to be more consistent.
  - Some people feel like they face a battle to get the medication which best suits their condition.
  - *"….on researching the medication prescribed for the illness [she] became aware of some of the major side effects. Due to perseverance and countless visits to her GP, she insisted on her medication to be reviewed"*
  - *"….doctors didn't accept my word about contraindications so I had to argue about what food and what other medication I could take with my specialist Parkinson's medication."*
  - Also, people want to have access to and choice of alternative, holistic therapies and treatment such as reflexology or acupuncture.

- Increasing the flexibility in accessing services, for example being able to book appointments out of work hours, being able to access walk-in centres with extended opening hours, and being able to get an urgent appointment, in between routine appointments, if they have concerns related to their condition.
  - *"Diabetics get a yearly check-up and yearly eye and foot checks. If I get concerned before then I am told there is no need for more frequent appointments and made to feel a nuisance"*

- o For some patient's, attending a hospital appointment is not in their best interest, so having services which are flexible and responsive to individual patient's needs would be beneficial.
- o *"My mum has dementia. She lives in a care home and needs a regular gynaecological procedure that could be done at home. However, she has to attend a hospital appointment where she becomes distressed and stroppy and because of this it is not always possible for the procedure to be carried out."*

- For Care Closer to Home/Supported Self Care to work it will be essential to build on and develop new ways to deliver support in the community, and people have concerns about how this will be achieved.
  - o Some people want to be able to access local, community-based support to help them manage long term conditions. This could include education programmes, support groups, social groups, activity groups, peer support and local hubs.
  - o Groups and one-to-one support could be delivered/supported by local volunteers, possibly asking people dealing with similar long term conditions to become involved.
  - o One participant said she would love the opportunity to support other diabetes patients with understanding illness, strategies to coping with illness approaches to de-stressing using holistic approaches.

- Increasing awareness of services that are not directly linked to their diagnosis, but that could offer them support, such as counselling services.
  - o People with long term conditions often feel a huge amount of strain which can affect confidence, self-esteem, independence, finances and relationships with family and friend. This can all lead to stress, anxiety and depression. People reported that they were not aware of counselling services to help them cope with their diagnosis and the subsequent impact on their lives.
  - o Also, the impact on carers, friends and family should not be underestimated.

- Concerns about how 'Supported Self Care' will work in practice. Concerns mainly relate to how and where services can be delivered in the community and the extra burden this might put on already over-stretched GP services.
  - o Some people prefer going to the hospital for their appointments because *'the hospital has more autonomy and …they were in much safer hands with people having higher levels of expertise'.*

2.6 Specific themes raised by protected groups

Some of the engagement and consultation that has taken place has been analysed to establish if there is any variation in the views expressed by people from protected groups. In addition to this, some pieces of work have focused on specific protected

groups; these have included people with learning disabilities; young parents; BME communities; young white working-class communities; and emerging communities.

The key themes raised by protected groups were: make sure in order of reports as above

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compared to 21.9% of disabled people in the sample. Similarly, fewer carers used smartphones than the full sample, but more than disabled people, at 32.7%.
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However, when looking at disabled people and carers there is a striking difference with substantially fewer disabled people and carers having use of the internet proportionately.
The majority of people did not have concerns about sharing their care records until disabled people and carers were considered. Compared to 15% of the whole sample 31% of disabled people and 47% of cares had concerns about their care record being shared.

When the data was reviewed to consider telehealth there were very limited differences in whether different sexes and disabled and non-disabled people would consider telehealth as a way of self-caring. For carers and different age groups, there were some differences but they were not large.

In conclusion, there may need to be further engagement to understand more fully what protected groups feel about self-care, telehealth and shared care records. There are gaps for:
- Men
- Pregnancy and maternity
- Ethnicity and country of birth
- Age groups

The priorities for further learning and engagement would be to reach more diverse ethnic groups and younger people.

One of the main themes of the feedback was that the respondents suggested using schools and education to prepare people to care for themselves. It would be useful to test this with young people. Older people do need further enquiry to check how they feel about self-care, care records and telehealth and how they can be supported effectively as their reduced access to some of the tools in this survey sample would suggest that more work would be required to enable them to participate in any schemes effectively.

Care Closer to Home, Calderdale
In one of the focus groups coordinated by Health Connections people who accessed hospital services for their condition had to use interpreter services when they attend appointments. However, when newly diagnosed, they felt "it is not taken into consideration that due to language barriers, individuals will not necessarily understand how to cope with the illness".

2.7 West Yorkshire and Harrogate personalisation emerging themes engagement and consultation activity at a glance

(E= Engagement, C = Consultation)

Key themes	Bradford District and Craven	Calderdale	Harrogate and Rural District	Kirklees	Leeds	Wakefield	Key areas
Self-care needs to be supported		E		E		E	Some people are worried they won't have the right information or communication to support this. Confidence, skills, knowledge and training were needed (all free of charge)
Overall people were willing to be involved in their own health management	E	E	E	E	E	E	People said to make an informed decision they needed time and understanding of all options available
Clinicians need to be more person-centred		E		E		E	Have an understanding of the patient's lifestyle to decide the most appropriate treatment and also to be given the correct information
Online support was an option for information		E		E		E	Those surveyed said they would access support, help and get advice and information from the internet. More information is need on safe sites. Not everyone has access to online information or the capability to obtain online

							support so this needs to be in addition to existing support
Peoples understanding of self-care was keeping fit and healthy		E				E	Taking responsibility for your own health and wellbeing. Some described self-care as only looking after yourself when you're ill.
Barriers to self-care		E		E		E	Lack of knowledge, time, depression and personal issues such as caring responsibilities, money worries, confidence and lifestyle were all barriers. Over-reliance on the NHS to pick up ill health were also mentioned.
Specific support for mental health				E		E	People to talk to, where the person feels listened to and heard. Not feeling isolated with more awareness of the support available in local areas.
Specific support for people with cancer						E	More access to support at the end of treatment such as the right information at the right time and tailored to meet the needs of the patient, online support and peer support groups. People also wanted support to ensure individuals have the confidence and skills to manage their condition themselves.

Section 3 – Appendices

Appendix A – List of documents reviewed

1. Kirklees Operational and NHS Long Term Plan event May 2019 **(report not yet published)** will be available July 2019
   https://www.greaterhuddersfieldccg.nhs.uk/get-involved/consultations/you-said-we-did/

2. North Yorkshire County Council (March 2019) - My Health My Tech (report not yet published) http://www.nypartnerships.org.uk/myhealthmytech

3. Leeds Health and Care Plan (January 2019) - Coproducing Personalised Care: working with people. For more information about this work please contact Adults and Health Directorate, Leeds City Council

4. Yorkshire and Humber Care Record (Autumn 2018) - Joined Up Yorkshire and Humber report
   https://www.wyhpartnership.co.uk/application/files/2615/4946/1753/Joined_Up_Yorkshire_and_Humber_2018_v2.pdf

5. NHS Bradford CCG (May 2018) - Frailty and technology, focus group engagement report https://www.bradforddistrictsccg.nhs.uk/seecmsfile/?id=1959

6. Connecting Care Wakefield District (February 2018) Self-care, telehealth and sharing care records engagement report
   https://www.wakefieldccg.nhs.uk/fileadmin/site_setup/contentUploads/Public_Information/Self_Care_Engagement_Report.pdf

7. Healthwatch engagement on 'Follow up Appointments' (April 2017)
   https://www.healthwatch.co.uk/reports-library/follow-appointments-engagement-report

8. NHS Greater Huddersfield CCG (March 2013 – August 2018) - Hospital engagement and consultation mapping report (Right Care, Right Time, Right Place Composite Report
   https://www.greaterhuddersfieldccg.nhs.uk/wp-content/uploads/2019/04/Final-Hospital-services-Composite-report-2013-2018.pdf

9. NHS Calderdale CCG (March 2013 – August 2018) – Care Closer to Home Calderdale published as an insert in Right Care, Right Time, Right Place Composite Report
   https://www.calderdaleccg.nhs.uk/download/composite-report-right-care-right-time-right-place/?wpdmdl=10867&ind=1537878093784

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