

## South Yorkshire Integrated Care System



### **Review of existing patient and public insight to inform the development of South Yorkshire's Integrated Care Strategy**

*Report prepared for the Integrated Care Partnership in South Yorkshire*

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# 1 Introduction and approach

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## 1.1 Background

The Integrated Care Partnership in South Yorkshire (ICP) is in the process of developing its inaugural Integrated Care Strategy for South Yorkshire.

The approach being taken by the ICP is to build on existing strategies and plans that are in place, in particular Health and Wellbeing strategies, and to develop a strategy which will be dynamic, evolving over time.

National guidance is that the ICP strategies should cover the following themes:

- Personalised care (to enhance personalisation, choice and flexibility for people who draw on health and adult social care services)
- Disparities in health and social care (addressing disparities in access, outcomes, and experiences of health and social care across the population)
- Population health and prevention (how to improve health and wellbeing and how to support prevention of physical and mental ill-health, future care and support needs, the loss of independence and premature mortality)
- Health protection (including infection and prevention control (tackling antimicrobial resistance; immunisation)
- Babies, children, young people, their families and health ageing
- ‘Health-related’ services (services which have a substantial impact on health and wellbeing but are not provided by a health or social care provider. This includes those impacting on wider determinants, such as employment and housing)
- Digital access

The ICP wants to ensure the work to develop the ambitions and priorities for health and care in South Yorkshire is informed by the views of patients and the public. To inform this early strategy development and build upon existing insight, The Campaign Company (TCC) has been commissioned to review engagement work within the above themes that has been undertaken by ICP partners in recent years.

This review will help to identify key themes but also identify potential gaps in the current engagement activity to further inform the development of the ICP strategy.

## 1.2 Methodology

The approach to this desk-based review covered the following aspects:

- Reviewing existing insight and engagement reports, held by engagement leads across South Yorkshire, including reports from Trusts, CCGs, local authorities and third sector partners;
- Reviewing data available via regular reporting mechanisms, including experience surveys and compliments and complaints reports;
- Examining available data on local and national websites, including the national Healthwatch report library, South Yorkshire Health and Wellbeing Boards and Overview and Scrutiny Committees.

Through this process 286 documents were reviewed.

## 2 Findings by strategic theme

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### 2.1 Personalised care

The existing insight and data show a number of key themes that are important to people across South Yorkshire in receiving personalised care.

#### *Choice*

Choice is a recurrent theme in the feedback reviewed around personalised care and this can be broken down into choice around the times in which people are able to access services; the location; and, increasingly, the type of appointment offered.

For time, where insight around extended hours for GPs had been gathered these changes were broadly welcomed, in particular people being able to access services in the evenings. However, access to GP appointments during the day were largely found to be inconvenient and time-consuming, especially when patients are given a telephone appointment without a time allocated to this.

There is a wide variety of insight around where people want to receive health and care services. People across South Yorkshire are well versed in travelling outside of their home area to access the services they need, particularly for specialist services, and other services have also more recently been adapted in response to the Covid-19 pandemic.

Generally, people support the notion of care closer to home with a belief that this will reduce travel times and cost, speed up recovery and keep the impact on caring responsibilities to a minimum. Yet people are also happy to travel to receive the best possible, highest quality care and know that they are in the right place should complications arise.

#### *Communication and information*

Communication between professionals and patients, carers and families is fundamental in how people feel about the care they receive.

When communication is open and clear and people receive information that allows them to be involved in and make decisions about their care, this contributes to the sense that people are more likely to view their overall experience positively. On the other hand, if there is a lack of clarity or appropriate information, many services reported people feeling less positive about their care.

The means of communication and information sharing is also an increasing element within this. Whilst this is discussed further within the digital access theme (2.7), it also links to choice in how people receive information – for some email and online communications is preferred but for others this feels inappropriate due to access, digital literacy and other issues.

Within much healthcare service feedback, in particular hospital provided services in Sheffield and Rotherham, patients and families generally express high levels of satisfaction with the care they receive. However, key issues that could be improved are communication and information between health and social care professionals and patients and families.

### ***Treating the patient as a person***

There is much feedback around patients being treated as a person rather than a series of separate issues accessing a range of different services. Particular examples of this were seen in Barnsley, where challenges in accessing social care during pandemic and frustrations about being ill equipped to deal with discharge from hospital were referenced by carers.

Some people in Doncaster accessing cancer services also felt that a consistent offer of emotional and, where appropriate, financial support as well as the provision of services at weekends to ensure consistency would be welcomed.

### ***Supported self-management***

It is clear that people want to manage their own health and well-being as much as possible: there was some feedback about some of the positive impacts this made on patients' well-being, confidence and recovery. However, many felt that the support needed to do this was lacking.

An important element identified in being effectively supported to manage their own care was establishing trust with a dedicated health care professional. This was strongly felt by cancer patients and others with long-term conditions. However, many felt that because there never appeared to be any consistency in the people they saw at appointments then they would doubt both the advice given by health-care professionals (since sometimes this was conflicting) and ultimately the decisions they were making about their own care.

From a different perspective, there were some people (particularly those who were older and more vulnerable) who felt that there was an increasing expectation from health-care professionals for them to manage their care themselves but they felt they did not have access to the appropriate support, tools and knowledge to be able to do this. This included not feeling confident with digital tools to access information; an anxiety that they could not trust their own decisions because they were not health experts; and not wanting responsibility for care budgets because they may not make informed decisions relating to this. Carers also felt that they should have equal access to the tools, knowledge and support provided to patients as part of personalised care packages because they were often best placed to make the most informed decisions about a patient's care. This was strongly felt by carers of people suffering from mental health conditions.

Some of the ways suggested to overcome these barriers were more information, the time and space to be able to discuss this information with a trusted healthcare professional – not someone who was going to ‘rush’ them; and learning and sharing with others who were in similar positions.

## 2.2 Disparities in health and social care

The Health and Wellbeing strategies of Barnsley, Doncaster, Rotherham and Sheffield set out priorities for their place and strategies for reducing health inequalities within each borough. These strategies identify a number of individual and societal factors that contribute to health inequalities including:

- Socio-economic status and deprivation – for example low income, living in a deprived area, and factors associated with this such as poor housing and educational attainment
- Vulnerable and socially excluded groups – for example refugees; Gypsy, Roma and traveller communities; unpaid carers; and people experiencing mental health conditions
- Protected characteristics – including age; sex; disability; pregnancy and maternity; and race
- Geography – including rural areas

*NB: The list above focusses on priority areas identified within the strategies.*

There has been a drive across South Yorkshire to improve the health status of people who may be impacted by these factors. Within the data and insight reviewed, there is feedback on areas where disparities in access to care; experience of care and behavioural risks to care are experienced by these groups. NB: There is more information on wider population experiences of these in sections 2.3, 2.6 and 2.8. This section focusses on the feedback of groups / key audiences who have more challenging experiences in accessing care.

### ***Behavioural risks***

Unhealthy behaviours such as smoking, poor diet, physical inactivity and harmful alcohol consumption are key factors that can lead to preventable ill-health. There have been many public health campaigns and interventions carried out across South Yorkshire to improve awareness of how these factors can impact on health. This has led to a general awareness across the wider population but there are still some groups who are less aware primarily because of socio-economic and other factors. These include:

- *Literacy levels* – this particularly impacts people for whom English is not their first language and people with lower educational attainment. Digital literacy has also been mentioned as an issue among older people.
- *Cultural factors* – for example dietary expectations among BAME groups and White British families on low incomes; social norms around drinking and smoking particularly among younger people but also older white British males
- *Availability of information* – not knowing where to find information; lack of clear information; and sometimes the limited channels in which information is available (written only; online only) are barriers to increasing awareness. This has been mentioned by newcomers to an area and socially excluded groups (eg traveller communities).



- *Affordability* – some people mention that switching diets (eg to eat healthy foods; to move to gluten-free options, etc) is more expensive than the pre-cooked or fast food alternatives. This has started to be mentioned in the context of cost of living issues. Going to the gym or cycling have also been mentioned as expensive or unsafe activities.
- *Capability* – some people lack confidence in their abilities to take action to increase healthy behaviours. Some people have mentioned the fact that they lack confidence or tools to cook; the lack of confidence to fully understand information presented to them has also been mentioned particularly by migrant, older and more vulnerable groups. The space to have conversations with trusted peers rather than rely on written information has been mentioned as a way of overcoming these barriers.

### ***Access to care and information***

How information is provided – both about appointments and accessing care and subsequent treatment - was raised as an issue in a variety of settings for a variety of people. This included a lack of information in primary care and relating to Covid-19 for those who require an Easy Read format and those for whom English is not a first language.

Carers also strongly felt that they did not have access to information that could support the way care could be provided to the patients they were looking after. Some said that it was challenging to navigate the health and care system if information was not provided directly to them and if they did not have the ‘authority’ to speak on a patient’s behalf. Another issue is that many did not always see themselves as carers and, as such, were not aware that support did exist for carers.

Those who do not have access to their own transport (both patients and carers) detailed this having an impact on accessing a range of services and influencing which services they would choose to use, from out of hours GP services and walk-in centres only accessible via multiple bus journeys to the location of vaccination clinics being too far away.

People who experience conditions that they perceive to have ‘stigma’ attached to them eg mental health conditions, substance abuse and sexual health conditions report that it is difficult to easily find support for their care that they would regard as confidential, non-judgemental and accessible.

Working patterns were also reported as having an impact on access to some healthcare services, this was particularly the case for health and wellbeing, vaccination and primary care services.

### ***Quality and experience of care***

While the insight around digital access is discussed in more detail in 2.7, digital exclusion was an issue raised by particular groups within communities as a specific barrier influencing their access and experience of health and social care services. For example for traveller communities in Doncaster and older people in Rotherham accessing the Covid-19 vaccine.

It is clear that more and more services are moving towards communicating and delivering services virtually using digital means but for many who are digitally excluded this will raise the divide in access to services further unless it is addressed.

For some, texts were seen as more acceptable than emails but any communications needs to be clear and well-written.

Several areas reported the issue of many services moving to online video or telephone appointments and the barriers this rose for people who are deaf or hard of hearing. Similar issues were also raised for those who do not have English as a first language when accessing telephone or video calls. Face to face was still seen as the best way to deliver services.

### ***Wider determinants of health***

It is recognised that wider determinants of health including income, education, access to green space, healthy diets, quality of housing and jobs have an impact on health. It is also recognised in the Health and Wellbeing strategies developed in Barnsley, Doncaster, Rotherham and Sheffield that inequalities and disparities in health are impacted by these factors but also in areas of deprivation. These are discussed in more detail in section 2.6 but it must be noted here that many of the groups noted above (eg low income groups; refugees and migrants) live in crowded or sub-standard housing; have lower educational attainment and are in insecure employment.

## 2.3 Population health and prevention

There are two key issues that have been identified when reviewing this section: mental health and well-being and health prevention.

### ***Mental health and well-being***

It was recognised by commissioners, providers and patients that mental health needs have increased significantly since COVID. It was felt that within this context much more work needed to be done to raise awareness of signs and symptoms of mental health conditions from depression to dementia so that early action and support could be provided to avoid chronic stages of these conditions.

Feedback from patients involved in developing Children and Adolescent Mental Health Services (CAMHS) in Rotherham and Barnsley suggested that:

- assessment waiting times should be improved – some young people had to resort to paying for their own care so that they could get timely support;
- better signposting of supporting services (eg welfare advice) should be provided;
- more advice and information for families and carers should be provided

There was also consensus that support for emotional, behavioural or mental health issues should be provided face-to-face rather than through other channels although signposting information was welcome in all formats (written, online and phone).

Being supported to have control of decisions was welcome by many but they felt that a lack of awareness and knowledge of what support services existed prevented them from doing so. This often led to people either taking no action or doubting the decisions they were making. This was particularly felt by younger people.

There was also recognition among all stakeholders that mental health and well-being was an area where a holistic person-centred approach was essential among all services and that this is where an integrated care strategy could have a huge impact.

### ***Health prevention***

Much has been done across South Yorkshire to raise awareness about the link between behaviours such as smoking, poor diet, physical inactivity and excessive alcohol consumption on preventable diseases. There has been increased awareness of campaigns and health promotion activities on these issues. [NB: Section 2.2 talks about some groups who are less aware primarily because of socio-economic and other factors.]

Awareness of campaigns encouraging COVID safe behaviours was also mentioned in a positive way. However, there was confusion about what the status of “COVID” was now and how people could continue “living with COVID safely”

Some people say that these health promotion initiatives could be improved by providing information in different formats targeted to different audiences for example videos, posters and social media posts. Many also suggested that a combination of written / oral information followed up with the ability to have a conversation with a health-care professional would allow them to have the agency to make informed decision and take the right action around their health. Others felt that there should also be more information shared locally and in day-to-day settings such as workplaces, education settings and retail outlets.

As well as prevention, there was also considerable feedback on early detection and diagnosis in order to stop conditions reaching chronic stages. It was felt that better health education for healthcare professionals as well as individuals to recognise signs and symptoms of a range of conditions (including different types of cancer, food intolerance, cardio-vascular diseases etc) would help save lives.

In terms of improving prevention and early diagnosis, it was felt that more could be done to help people navigate the ‘system’. This was particularly felt by people who had lower levels of health literacy (in the context the knowledge, capacity and confidence to access and use information to make decisions about health) and digital literacy. Access to peer support and community champions to help with this was also mentioned as a potential way of overcoming these barriers.

Long COVID was also mentioned as an increasing worry. People felt that there should be much more information about potential symptoms and that referrals to assessment centres should be quicker. It was also felt that more education with employers was needed to support people who were potentially suffering from long COVID.

## 2.4 Health protection

The main references to this were around immunisation programmes.

### ***Attitudes to COVID vaccine***

Those who had concerns about the Covid vaccine cited concerns about safety, insufficient information about the vaccine, information on social media and concerns about its impact on fertility. Trust in the vaccine was a particular concern for BAME and newly arrived migrants.

There were generally high levels of satisfaction with the vaccination process and access to vaccine centres in all areas.

### ***Attitudes to flu vaccines***

There is a higher level of trust in flu jabs and satisfaction with the process of receiving flu jab than with COVID vaccines since they are longer established.

People would like to see more choice in where and when to receive flu jabs (similarly to the flexibility in where and when to get COVID vaccines. GP practices are still seen as the preferred choice for receiving these because they are perceived as local “health hubs”. However there were a number of suggestions made for providing alternative flexible local provision including drive-through centres, mobile clinics and community pharmacies.

## 2.5 Babies, children, young people, their families and healthy ageing

This section identifies experiences shared within a ‘whole-family’ approach but there are many linkages with individual experiences described in other sections of the report.

### *Supporting carers*

There is a strong need to recognise the needs of unpaid carers who support family members who may be older or younger. Some of these needs have been identified elsewhere (see section 2.2) but include the need to have more information about patients’ care needs; the need to be more involved when decisions are made about a patient’s care; and to recognise that they need support themselves as carer (eg respite care). Some people mentioned that the only type of support that is available can be vouchers for the gym or ‘me-time’ yet they do not have the time or means to leave the person they are caring for to benefit from these.

Young carers also have specific needs that need to be recognised. They are often juggling many responsibilities including study, work, caring and would benefit from respite too. Young carers in Barnsley have identified respite through social activities as a need.

### *Transition points*

There are some key transition points that have been identified by people where people feel they are no longer supported by the system or do not know where they can continue receiving care. Some mentioned include:

- becoming a parent – there is mixed feedback from people using maternity services for example including from MS sufferers and people from BAME communities who feel that cultural factors are not taken into account
- accessing children’s services – continuity from maternity services to children’s services appears to be poor particularly from parents whose children have a childhood condition. Some have felt that signposting is poor and feel unsupported by GPs.
- Transitioning from children’s social care to adult social care – this has been particularly mentioned by young people experiencing mental health conditions: they feel fully supported as a “child” but find it difficult to navigate the “adult” system and are reluctant to lose the connection with a trusted healthcare professional
- receiving care as an older person – some people have felt patronised and subsequently ‘diminished’ when they are obliged to receive care due to physical conditions. They feel that the support for them to live at home is not there. Some carers supporting people with dementia also feel that they are not treated with respect or dignity and that their contributions to decisions relating to the patients care are not taken into account.

## 2.6 Wider determinants of health

National guidance on developing Integrated Care Strategies recognises that there are some services that have a substantial impact on health and well-being but are not provided by a health or social care provider. These 'health-related' services generally tend to impact on wider determinants of health, such as housing and employment. As such, how these could work more closely with health and social care services is an important consideration in the development of South Yorkshire ICP's strategy.

The insight and data reviewed shows that commissioners and providers recognise the impact of wider determinants of health on individuals and also the way that they may contribute to health inequalities (see section 2.2). These are clearly identified in the Health and Wellbeing strategies for Barnsley, Doncaster, Rotherham and Sheffield.

As would be expected, since the data reviewed in this research was primarily collected by health commissioners / providers then patients' experience of 'health-services' and wider determinants of health are not explicitly stated. However, there are some elements in the feedback that implicitly suggest how wider determinants of health impact on their health and well-being. It should be noted that a lot of the feedback where this is raised appears to be from patients and families who live in areas of higher deprivation (probably because much engagement has been carried out in areas where there are poorer health outcomes).

### ***Feeling safe***

Safety was mentioned at both an individual and community level. Being a victim of violence (domestic and neighbourhood) was specifically mentioned by users of urgent and emergency care services. Some people with mental health issues, including those triggered by social isolation, sometimes mentioned the fact that they feared going out because they lived in areas that were not safe.

Accessing health and care services in safe and familiar places was often cited as a driver, especially among older people, for wanting services closer to home.

Living in areas that were not safe, was also cited as a barrier to undertaking outdoor physical activity (eg walking, running and cycling).

### ***Access to learning***

Places of learning (eg schools, colleges and adult-learning environments) were cited as places where health information could be distributed and also health education could take place. Encouraging children and young people to adopt healthy behaviours and educating them about the benefits of this at early ages was often mentioned.

As well as places to promote healthy activity, these settings were also mentioned as places where services could be signposted especially those where privacy and confidentiality were seen as important including sexual health services, mental health services, etc.

Teachers / educators were also mentioned as important trusted channels who could be equipped not just to share health information but also to spot any signs and symptoms of conditions such as mental health or abuse.

Low levels of literacy and numeracy were also mentioned by stakeholders and carers as factors that impacted patients' agency and ability to sometimes make informed decisions about care but also to manage their own care.

### ***Housing***

The impact of housing conditions was mentioned by some as a contributor to their and their families physical and mental health and well-being. Some people mentioned damp and mould as factors that exacerbated respiratory conditions (eg asthma) of family members of all ages.

Over-crowded conditions, particularly mentioned by social housing tenants, were mentioned as a factor in quickly spreading contagious illnesses such as COVID-19.

Practical support to make adaptations in the home to allow people with disabilities or older people to live independently at home was also raised as solutions that could impact on well-being by promoting self-confidence and self-esteem.

### ***Transport***

One of the biggest factors affecting people's experience of health and social care is transport. This is cited by both patients and carers / families. People reliant on public transport think that more efforts should be made to make sure that there are better links to hospitals and specialist care settings ('better' in this context is the frequency; the extent to which there is integration between trains and busses; and availability of transport at certain times eg evenings when people might be visiting patients). This issue is particularly raised by people who live in more rural areas. Parents of babies and toddlers in particular cite difficulties in using prams and push-chairs on public transport.

Affordability of travel is also mentioned as affecting people's experience with the cost of travel and the cost of parking being frequently mentioned.

Community transport solutions are mentioned by a small number of people as being able to support travel for patients who find it difficult to navigate public transport networks because of physical ailments or because other forms of transport (taxi or public transport) are too expensive. There are limitations identified with this including availability.

### ***Inclusive communities***

There is a recognition by stakeholders that there is a lot of movement within communities and that more efforts should be made to ensure that the health needs of refugees and migrant workers should be met. Both stakeholders and patients have suggested using



community settings, retail outlets that specialise in different ethnic foods and trusted local faith / community leaders would be effective channels to spread health messages and information about services to ‘newcomers’.

It was also reported by some refugees that COVID-related delays in certain statutory processes, for example asylum interviews carried out by the Home Office, has caused an additional impact on people’s mental health – people who are already fearing for their own future and the future of their families in their native countries.

### **Costs**

The cost of accessing services – whether it be travel, digital access, adopting healthy behaviours and the actual cost of care – was frequently mentioned as a growing anxiety. While most of the data reviewed dated before the cost of living crisis spiralled this year, this is clearly going to exacerbate some of these anxieties.

In terms of overcoming some of these anxieties, some people mentioned better signposting to some of the benefits or financial support that they could access. Others also mentioned being able to access better-paid jobs. The impact of COVID on working practices (especially more part-time working rather than full-time) was also mentioned by some as a factor that meant they now had lower disposable income than they did a few years ago.

## 2.7 Digital access

It is clear from reviewing the feedback, that the pandemic has changed attitudes and behaviours towards digital solutions in a positive way. Through necessity, people have become more adept and confident in using online health information and services. However, there are some groups that are still excluded or less able to access digital health care or just don't want to. Patient and family feedback suggest that this is down to three key reasons: affordability, skills and choice.

### ***Affordability***

Being able to afford internet access and/or equipment (eg smartphones, tablets, computers) to effectively use online services was more frequently mentioned as a barrier to digital inclusion than skills. Groups that are particularly impacted are those on lower or no incomes (including retirees) or more vulnerable groups (including refugee, asylum seekers and people with learning disabilities). As a result, people who did not have digital access often struggled to make appointments or ended up having to pay more for long automated telephone appointments which they also struggled to navigate)

### ***Skills***

Two key aspects to this were often mentioned: lack of confidence and knowledge to access digital health information / care (ie digital skills themselves) and also the difficulties of navigating the system and understanding information (ie digital health literacy). This was raised by more vulnerable groups such as older people and people with learning disabilities. Some people felt pushed towards using online systems such as NHS 111 which they did not feel confident in using stating that they would prefer to have a conversation with someone.

### ***Choice***

There was consensus that digital health services should be part of the solution and not the whole solution. Having the options to choose what worked best for people was seen as key. There was a strong feeling that face-to-face interactions were best but there was also a recognition that digitalisation could also help make parts of a patients care journey more effective. The NHS app was universally seen as a positive development – the ability to order prescriptions, sending messages to GP, being able to search online for advice were all cited as features that were positive. However, some people wanted to access more information about their health on this including records from both primary and secondary care providers as well as have the ability to communicate with secondary care professionals in the same way as they could their GP.

One element that affected choice too was concerns about how health and personal data was used and shared. This was particularly raised by young people. Choosing how to receive

information (eg by e-mail, text, post, or phone) was also seen as an important element of patient choice.

It was also recognised that pre-op assessments or monitoring conversations with consultants were also more efficient. These meetings were generally 15 minutes but could take an hour to get too.

### 3 Conclusions

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From the insight reviewed, it is clear that every person experiences care in a way that is shaped by circumstances unique to them – from individual and behavioural traits, environmental factors including interactions with the health and social care system, and the social context within which they live. Because of this, it is sometimes difficult to extrapolate individual and subjective feelings into a strategic context. Notwithstanding that, this report has attempted to summarise key findings into the framework set out by NHS England to help ICPs develop an Integrated Care Strategy for each of their areas.

Because of the wealth of information collected from patients and their families across Barnsley, Doncaster, Rotherham and Sheffield over recent years, it is possible to see that there are universal themes, crossing different medical conditions and services, that can usefully inform the development of South Yorkshire's Integrated Care Strategy. These universal themes, identified by patients and families as important elements in their care, have been summarised as follows:

- **Awareness** – this includes the need for more information about health prevention and availability of different health and social care services.
- **Access** – this includes removing the barriers to accessing health and social care services. It is important to note that people's experiences of accessing services have also been made within the context of the pandemic.
- **Agency** – this includes providing people with the information, tools and capacity to manage their own care.

More detail of these, as referenced throughout this report, are summarised below.

#### **Awareness**

One of the biggest barriers to better health and well-being appears to be a general lack of awareness of information and support about how to live healthily but also what exists to support ill-health. This was particularly mentioned within the following contexts:

- *Living well* – while there is more generally awareness of factors such as smoking, poor diet, lack of exercise, etc on health conditions such as diabetes, cancer, cardio-vascular conditions, there is a demand for more information and particularly practical support on how to prevent these conditions. This is particularly mentioned by specific groups such as older men, lone parents, people with disabilities, newcomers to an area (including refugees) and those living transient lifestyles (including students and Traveller, Gypsy and Roma communities).
- *Spotting signs and symptoms of long-term conditions* – better support for early detection and diagnosis of cancer, dementia, depression and other conditions (including food tolerance) were regularly mentioned. There are specifically two issues here: not

knowing what to look for but also not knowing who to talk to about concerns. The difficulty in getting GP appointments has exacerbated this as well as a mind-set of 'it's probably nothing'. People do not appear to be aware that there are other information sources or experts that they could approach instead.

- *Support for carers* – a common theme, particularly for people with long-term conditions including mental health, is the lack of support for carers including young carers. Some people do not know what, if anything, exists: others feel that what is offered (eg vouchers) is not appropriate.

### **Access**

Accessing services is one of the most commonly mentioned areas of concern by patients and families not least because it affects the quality of a patient's experience. Access in this review covered many dimensions including:

- Accessing health and social care services that are locally provided and close to home. It was felt that this would overcome practical barriers such as 'getting there', the time to get there and the reassurance of receiving care in a familiar community environment.
- Affordability – this primarily focussed on cost of transport, cost of parking, cost of medication and the cost of care (particularly mentioned by older people). The cost of digital care was also mentioned in this context – some people were concerned about the cost of broadband and equipment needed to support tele or video consults or virtual carer / patient conversations if a patient was in a hospital / care setting.
- Access to GP services was frequently mentioned as being challenging – particularly during and since COVID lockdowns. Getting an appointment; the booking process and even the quality of interaction within a GP practice (including the lack of signposting by GP and practice staff) were all factors that were cited in this context. It was recognised that a lack of response from a GP would lead to people using urgent and emergency care services instead.
- People not knowing what services can be accessed (see *awareness* section)

### **Agency**

Most people want to be in control of their care and many are frustrated by the barriers that prevent this. People welcome the opportunity that digital solutions such as the NHS App present in terms of managing medication, appointments and so on but some want more from this – eg access to medical records.

A number of people, particularly more vulnerable groups, are reliant on the “system” but struggle to navigate it. Carers in particular wish they had access to more information so that they could better support the people they care for. They also wish they had similar levels of ‘rights’ as a patient so that decisions about a patient’s care could be made as a “family”.

Spaces to have “conversations” rather than just information in written form was also suggested by people including those with lower educational attainments, people for whom English was not their first language, younger people and others who wanted to have “agency” over their decisions. Trusted third parties were also felt to be a good way of sharing information and having confidential conversations about health matters.

It was also recognised that sometimes lack of agency was mainly due to a lack of information so providing health information in places where people “were at” (eg workplaces, educational establishments, social places) would help people take control of their care.

### ***Next steps***

As part of this review process, it is clear that there is much information available about mental health and well-being services; the experiences of carers and young carers; specific conditions especially in secondary care settings; and BAME groups in areas such as Sheffield. Engagement reports provided by Healthwatch bodies across South Yorkshire was also extensive.

The next phase of this work provides an opportunity to make sure that the voice of all the key under-represented and socially excluded groups within South Yorkshire are heard (either directly or through third-party advocates).

There is also an opportunity to make sure that organisations that impact on the wider determinants of health (eg housing associations, police, employers, educational establishments, etc) are also engaged in the development of an integrated care strategy as well as providers of social care.