

Digitising Care

Views of family carers of people with a learning disability



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1. Headlines

The family carers involved

- Ten family carers and one sibling carer, aged 18-80+ years were interviewed for this report
- Seven had their family members at home, three were in supported living and one in an ATU
- The ten family members with learning disabilities, being cared for were aged 8-54 years and three have complex conditions – one of whom has a rare disease.

What family carers said about digitising services

Making the call

- Family carers, usually the mother, make and manage all the medical appointments for their family members living at home – a serious responsibility where they are assessing and balancing risks.
- Supported living providers took responsibility for the medical care of people they support, but family carers often needed to be involved.

Who is online?

- Family carers aged 79 and 80+ said they did not feel confident using any online services at all – though they carried a mobile phone for emergencies; they always used and preferred a landline or failing that, letters to contact medical professionals.
- Older carers in their 70s- 80s focused on needing confidence to use ‘new’ technology, furthermore, they do not have the hardware and software in place.
- Younger family carers 18-60 years had a variety of technology at home and were reasonably if not totally confident about using it, they also needed additional equipment such as printer and scanners though to record and share information.

What works now?

- Family carers in their 50s and below used a few of the online services on offer from GPs, dentists and for specialist referrals but preferred to use the phone, primarily because their family members need reasonable adjustments not built into the online systems.

- All family carers had limited knowledge that digital Assistive Technology (ATT) exists and its advantages on mobiles, laptops and PC.
- Websites and apps are not used frequently for medical health management or information about their family member. Most had tried but discovered that their family member's situation is unique requiring tailored specialist advice.

Managing safety

- Family carers felt they were not managing passwords securely.
- Confidentiality and security about medical information contained in images and videos were a concern.
- Digital systems that do not communicate and organisational barriers which prevented the carers and professionals sharing information, cause frustration and distrust.
- Managing the volume and complexity of the medical information about their son or daughter on online and offline systems is time consuming and burdensome.

Skills and knowledge

- The level skills and knowledge family carers need to have before they make any contact with medical professionals online or offline is formidable, ranging from knowledge of the Mental Capacity Act to how to challenge poor practice.
- Family carers need to know why it offers better care than the current arrangements they have worked extremely hard to establish, as they are able to learn new digital skills and use new services.

Barriers to using online services

- Being physically prevented from using a laptop or PC by their family member with learning disabilities.
- That the experience of an online consultation for their son or daughter would reduce their presence and 'voice' - that they would not have a voice but rely too heavily on the family carer to interpret and translate for them.
- The quality of the interaction with the medical professional, could be reduced by the technology itself – e.g unstable connection thus leading to poorer decision making especially if the clinician is unknown to the family.
- That the relationship between the medical professional and their patient would be eroded and even dehumanizing for both parties.

Advantages to online services

- For a family member who is safer or more comfortable at home the experience could be less stressful, save travel time, parking and be quicker.
- Fewer mistakes when ordering medication and access to patient records were also seen as an advantage
- Using inbuilt, interpretation, translation, visual guides, videos and illustrations were all seen as ways of giving a better service online

Conclusion

Older family carers 70s+ do not have the confidence, skills and equipment needed to convert to fully online services to support their family members. They will need alternatives to online only services.

Family carers will use online services if they know about them, can quickly and can easily use them. But... they must they offer better care than current arrangement they have worked for years to get in place.

Regardless of age or digital literacy where reasonable adjustments are needed, health conditions are complex and personal relationships with medical professionals are paramount for the quality of care, family carers will always seek to reduce the risk by whatever means is possible.

Family carers who are not first language users of British English, face increased barriers when using online services. However, opportunities to improve digital services are growing and embedding interpretation and translation options are already out there.

1. Oxfordshire Family Support Network - OXFSN

OXFSN is a charity founded over ten years ago by family carers of children and adults with a learning disability. It has one aim: to get a good life for people with learning disabilities by informing, involving and inspiring their families.

OXFSN created and maintains a strong and effective network of family carers, helping to bring people together, break isolation and enable family carers to access the support.

OXFSN also brings a voice to family carers, representing them at the highest decision- making level locally and ensuring their reality is recognised by health and social care services.

The key areas of work are:

- Provision of information, advice, guidance, resources to family carers
- Advocacy and support to family carers
- Accredited training for families and professionals
- Family Carer representation and involvement with health and social care decision makers, locally and nationally including the Transforming care board
- Quality Checkers programme

2. Definitions of Family Carer and Professional

The term 'family carer' refers to an adult who cares for an immediate member of their family with a learning disability. In most cases this is a parent, though it is also a sibling. OXFSN use family carer to identify and respect the lived experience of an unpaid family carer, as opposed to the professional and paid relationship of a carer i.e. who is a support worker or personal assistant

The term 'professional' refers to paid staff in care provider organisations, and in statutory primary and secondary health and social care services i.e. social workers, psychologists, physiotherapists, behaviour support staff, speech and language therapists, GPs, dentists).

3. Aim

Health and social care services in primary and secondary care are increasing using online or digitized systems to provide some or all of their services to their patients (clients or service users). For some people this can be a fast and effective way of accessing services and information.

However, there is increasing recognition that ‘digital exclusion’ is most common among the elderly, those on a low income and people with learning disabilities.

This report supports the work of the Personalised Care Group in understanding how it can best ensure that digital tools and solutions for personalised care, meet the needs of family carers who support a family member with a learning disability to reduce digital exclusion.

This report will identify

- The ways in which some family carers of adults and children with learning disabilities currently use digital platforms and access digital information
- Which demographics are most likely to use digital tools
- Which demographics are likely to be the most excluded and why
- Barriers for family carers accessing digital media
- Skills, knowledge and experience needed by family to access digital media
- Identify system issues needing consideration to remove barriers (presentation and making info more accessible)

4. Scope

This report shares a range of responses from family carers and highlights they are experiencing. It does not claim or aim to be statistically accurate, but to raise key issues and opportunities which need further conversations or even formal research.

5. Methodology

During April 2020 OXFSN spoke to 10 family carers - and one sibling - of a son or daughter with learning disabilities. They were chosen to reflect a broad age range and the variety of living situations of their family member and the range of health needs that people with learning disabilities. More details are in **Appendix 1 table 1 and table 2**. Family carers responded to 10 questions by telephone interview **Appendix 2** has the full survey. The intention had been to interview face to face, but the COVID-19 lockdown prevented any face to face contact.

Additional sources of information used in this report were sourced from OXFSN’s publication available on our website: <https://www.oxfsn.org.uk/category/resources/publications/>

Feedback from three accredited Family Champions Courses 2017-2020

6. Profiles

Family Carer Profiles

10 family carers - and one sibling - of a son or daughter with learning disabilities were interviewed.

- Family carers ranged from 18 to 80+ years, the 18-year-old is a sibling
- Nine women and two men
- Seven are caring for their child at home
- Four have a child in supported living
- One person is in an ATU (Assessment and Treatment Unit)

Profile of people with learning disabilities

Ten children, young people and adults with a learning disability are being cared for by the family carers interviewed.

- Ages: range from under 10s to 50s
- Gender: Eight are male and three are female
- Health: All ten have long term physical and mental health conditions and fall into 30% of population – see table 2
- Three have complex needs fall into the 5% of the population- see table 2; two are currently under the care of Great Ormond Street Hospital, London one is currently in an ATU.

7. Findings

Family carers were asked to response to a survey with 10 questions and then interviewed for up to an hour by telephone. **Appendix 1** has the fuller survey.

Q1: Who makes doctors, dental and hospital appointments for your family member?

Family carers who had a son/daughter at home made the appointments themselves, the two men reported that their wives made them. Support workers made all the appointments for those in supported living.

The relief of handing over the responsibility to the care providers to deal with this was cited by all family carers across all the age ranges and health conditions, indicating what a worry and burden managing health care is for family carers.

“It’s a relief that someone else is taking responsibility.” (G)

For specialist referrals e.g. MRI or mammograms family carers all said they needed to speak to a medical professional by phone to access to reasonable adjustments e.g. to get an MRI on a Saturday morning when there is less traffic and better parking.

“A call just reduces the steps in the process. Otherwise you have to go back to GP get another letter etc. Feels like they are trying to put you off, I just give up.” (D)

Q2: What ICT equipment do you own?

All respondents owned a mobile phone in addition to their landline, most owned a tablet, but only two had a PC. They also owned additional equipment included: laminators, scanners, photocopiers, printers and encrypted memory sticks and software.

“There’s an expectation you have a scanner.” (H)

“I am not very good, I get addled and frustrated trying to use the mobile.” (F)

Q3: Do you use any health apps and websites to support your family member?

The carers in their 70s and 80s did not use any websites, or apps relying solely on GP consultations for medical information, including the interpretation of hospital letters.

Carers in 30-50s were confident about using websites and apps- reflecting their use of social media (Facebook, Zoom, WhatsApp. However, as with the older carers, they went to medical and social care professionals for advice, information and interventions – rarely using websites and apps. They named only a handful of specific websites and apps including, NHS Health A-Z , WikiMe, MyGOSH. Concerns focused on the quality and accuracy of the information and the skills needs to get the information needed.

“It’s hard to find an authoritative video or illustrations which would be better in many cases” (E)

“You need to know where to look, how to pose the question, where to post your question and how to shift through the rubbish and non-applicable.” (E)

Family carers of the two children and one young adult with complex needs, did rely more heavily on websites for information about their child's condition, but also online support groups which provided additional information to help them navigate health and social care services.

"J is one of 20 in the world with his condition, so knowledge of [my son's] medical needs – only get it online – couldn't get it elsewhere." (H)

"I belonged to SWAN UK (syndrome without a name)– an online group for 7 years - learnt the terms- CAF, TAC etc. all the social care and health care terms" (H)

Q4. Do you currently use any online services related to healthcare?

Younger family carers used few of the online services on offer from GPs and dentists, preferring to use the phone – both mobile and landline for two reasons – the advantages were not clear to them whereas the barriers were- and their family members need reasonable adjustments not built into the online systems. However, one parent related an extremely positive experience in Covid-19 lockdown, with her son who has a rare disease, she was able to phone her consultant in London from Newcastle and arrange an online Zoom call with him, where he was able to assess her son and then he contacted a counterpart in Newcastle hospital to arrange for medication to be issued that day – which the child then received.

"When my daughter lived at home, I would call to book her annual health checks as the online system was not set up to book these as they needed extra time. For any prescriptions I would renew online. I prefer booking appointments etc. online other than, they can't always book far enough ahead". (D)

"I phone the surgery and says it's for my daughter and they fit her in for appointments. It needs a conversation" (F)

"He hasn't got a clue – he hands it over to me!"- talking about her husband receiving a text message from the surgery. (F)

"With signing up for patient records, I am not clear what the benefits are for me – I am not clear if I had to do it. "(J)

"As a lockdown response I had a Zoom meeting with the consultant at GOSH I rang, that day; I live in Newcastle, and I got meds that day." (H)

Q5 What assistive technology (ATT) do you use to help you access digital media?

No family carers used ATT. Three family carers said they increased the text size and one increased the volume using inbuilt facilities on their mobile phones and laptops. The older carers were not aware that ATT was available.

Q6. How do you manage passwords, confidentiality, and privacy issues for your family member?

Most family carers kept passwords in a separate notebook which they kept at home, or as note on their mobile phones. They were all concerned about password management thinking they are not doing this the best way. They were not aware of how the support providers managed passwords.

“Passwords are hard to manage – I use the Se for everyone- finger print and eye recognition technology would help” (D)

Confidentiality and privacy of information about their son and daughter was a concern for all family carers. However, they all put a significant amount of trust in the medical and social care professions to take responsibility for this.

“I may be wrong, but I feel that PMLD parents won’t worry about privacy and consent – J has no concept developmentally. It’s the speed accuracy of triage that matters.” (H)

“Privacy at the end- what happens to the images? Are they on a cloud or stored somewhere? (E)

They all felt frustrated by digitisation information sharing protocols between health and social care in particular, which are absent or confusing, this often means a letter or report cannot be emailed to another organisation.

Q7. What skills do you think you need to use the apps/ websites to help you manage your family member’s health?

All family carers all recognised they needed a range of skills use apps and websites, including:

- Being able to read and spell, write and type
- Using a keypad, keyboard and touch screen
- Feeling confident about, finding, downloading, and setting up online apps and using websites.

- Knowing the operating systems for Apple and Android, how to contact your internet provider, interpret and understand the minutes and data use to work out costs, setting up a printer and scanner, using memory sticks, clouds etc.
- Being able to spot and deal with identity fraud and get rid of adverts

“Need to be savvy and street wise to avoid scams and have secure information and confidentiality” (E)

“You need to know what an app is and how to get one and how to link it with your PC etc. I can be quite complicated.” (A)

Q8: What knowledge do you need to support your family member?

Family carers said they needed to have a detailed knowledge of their son and daughter needs and behaviors plus good working knowledge of the local and national health and social care services and polices legal rights and benefit entitlements. They acquired this primarily through peer support, experience both good and bad, supplemented by online services and information.

“I need to know what questions to ask, who to ask, whether the advice is best practice, who else needs to know. I need to know the law, key policies and when I need to challenge...and that’s before I have even picked up the phone.” (A)

“You have to be brave and assertive and you need contextual knowledge” (J)

A major issue was managing the volume and complexity of the information about their son or daughter – which increased in line with their medical needs. The family carers who have complex conditions to deal with spend hours every month, downloading, photocopying and filing, posting and emailing letters. They track missing letters and take copies for professionals to meetings where online systems have failed. They cited Wiki Me and the Great Ormond Street App My GOSH – which are there to support family carers and centre around the needs of the person with learning disabilities – a term we refer to as ‘person-centred’ in OXFSN.

“I need knowledge of Autism services, Oxford health, Information Systems Technology services and knowledge of how to handle him, very detailed e.g. pull out a cannula learnt from bitter experience the history of his needs and behaviors.” (C)

Q9: What worries and/or stops you about new services increasingly coming online?

Family carers said that physical access is an issue being actively prevented from getting to the computer, this included those with complex needs and those with long-term conditions.

“A would stop me using the computer for a meeting e.g. Zoom.” (C)

“My daughter will not sit in front of a screen and will wander off.” (D)

Worries for carers in their 50s and below, were rarely about the technology, though everyone cited experiences where they had given up on systems, they had tried to use because of difficulties with them, most commonly signing up to GP online services.

“A new system wouldn’t pose technical challenge, but the CTR (NHS clinical treatments and review) signup payment was really complicated so I gave up in the end asked for paper copies” (C)

Instead, concerns centred on the quality of the experience for their son or daughter, the quality of the interaction with the medical professional, that clinical decisions would be based on poor information and their child would not have a voice.

“I worry the consultation/conversation will be between the person supporting them, as they are not in the presence of the GP who can get to know them over time” (D).

“I worry also that nonverbal language and communication are not going to happen e.g. not picked up on screen and it’s easier to cut the conversation short”. (D)

With the exception of the older carers, family carers could see some advantages to online services for those who are safer or more comfortable at home the experience could be quicker, less stressful, save travel time, parking etc.

“In some ways its good, my son is less stressed in his home environment, and he was at his ease it could be quicker if there was a good image and good connection” (E)

“I normally have to arrange an ambulance to go to hospital with my son it was 3 hours each way – now I am in Newcastle it’s a 5-hour drive – unthinkable – with an overnight stay with full wheelchair access etc. (H)

Having a choice of appointments to book in their own time was helpful too, and access to patient records, e.g. hospital discharge letters and test results, to pass on to the myriad of professionals in their child’s care were also included. Online prescriptions are seen helpful as mistakes with medication quantities and timings were made by both GP practices and family carers.

“I liked the online Patient Access system from the GP, but I can only get a link password in person, occasionally it locks me out and I have to physically go the surgery to get a new password – they won’t email , post or phone it through- so I have stopped for now, (F)

“Worrying about messing things up in very efficient systems – and getting a negative response – but I have had nothing but good experiences. I am young and people see me in a certain way.” (J)

“What is the plan B when technology goes wrong?” (E)

The relationship with the medical professional was extremely important for the family carer, that they could ‘get to know’ their child, touch them and see them as human being. One parent felt that her child’s paediatrician also needed to see his young patient because he was human too and really cared about his patients.

“Empathy is important – a hand on the shoulder, my son is 8 and when examining him medical staff would hold hands with him. It’s dehumanising not to have face to face contact with him” (H)

“What does the doctor and the patient get back with online consultations? “Our children are already excluded from contact with others we don’t want to exclude them anymore” (H)

Q10: What support do you need to use a new online service?

Older carers were worried by the thought of having to cope with the technology required for online systems and had no confidence they would be able to manage.

“It’s not so easy to remember things in your 80s, tell me today and I forget in 3 days” (F)

The sibling carer was unconfident, not because of the technology but because of all the contextual knowledge and communication skills she needs before using a service.

“My lack of confidence, lack of experience – but I would get there, I really would.” (J)

“A letter or email explaining how to set up the service, use it and how to opt out is always helpful.” (C)

“A video taking me through it stop by step and plenty of forewarning about the change in the service, by email, by call, face to face. Tell me at the end of the appointment.” (J)

“I don’t need to make them appointments anymore as they are all handled by the support provider. However, I would wish to be kept informed of any visits/unexpected health visits etc. (G)

“I like the visuals on the First Direct online banking set up – they remind me each time how to use my key – I don’t have to remember”. (F)

“Advice on password management.” (H)

8. Key themes

This section summaries the main themes which family carers raised during this conversation.

Daily toll

For family carers managing the daily health and care needs of their family member at home it is a major priority. It uses up their time and energy and can be expensive – they have mobile phones and laptops, but few PCs and some have purchased scanners, printers, digital cameras, encrypted memory sticks. Bespoke software e.g. Wiki Me was praised too but carries an annual license fee.

Using any health care system whether online, by post, or by phone can quickly become a burden- the advantages need to be quick and clear. Multiple log-ins, collecting passwords in person, partial access and inaccurate information put them off instantly.

Shared responsibility and risk

Family carers take responsibility and balance risks daily to care for their family member for decades. Even with a family member in supported living or an Assessment and Treatment Units they want to be kept informed and involved, Family carers were worried that online consultations, for example would further shift the risk on to them as they interpret and translate for their son or daughter all of whom have language, communication and literacy difficulties. Being able to speak to a flexible receptionist means sharing that responsibility when sorting out these issues,

Opt out

Nationally more adults with learning disabilities live at home, than the average population, and these family carers are still managing the health care. F is in her 80s managing the health of her daughter, who lives at home. Some aspects of health appointments remain inaccessible to her daughter despite reasonable adjustments. Online appointment booking services are not something she can use and nor would she, as her daughter's needs are too complex in her view.

Relationships

All family carers in this study wanted a close working relationship with the health professionals in the life of their family members which included being close enough to hold their child's hand, get the tone of voice right and listening to the parent carers experiences, needs as they provide the care.

Social versus digital exclusion

Whilst digital exclusion is recognised as impacting negatively on those in poverty, older people and those with disabilities, family carers are far more concerned about the social exclusion their family members already experience. This means some family carers regarding digital consultations as a step further away from being part of a community or society rather than a step towards it.

Getting good information

Websites and apps are not used frequently for medical health management or information about their family member. Most had tried but discovered that their family member needs and situation are unique requiring tailored specialist advice. The MyGOSH app was warmly reviewed as it can be tailored to the family and the child, with copies of all consultants' letters, records of appointments, medications and has a facility to directly contact the child's consultant.

Systems that don't speak

Family carers meet scores of professionals over the years of looking after their child and become the record holder for their family members. All expressed frustration that, "my child's schools won't use video" (H). Health and social care systems are separate so occupational therapists cannot share letters with a social worker. The County Council will not use Zoom for a Child in Need team meeting even though the local hospital will. "The Egress system I need for social care, wipes all records after 4 weeks unless you download and copy you have no proof of what happened in that a meeting". (B)

Barriers

Family carers are using few of the online medical services currently available such as booking online appointments for GP and dental services, patient access to their online records GP records, repeat prescriptions services managed by an external pharmacy.

Reasons included not knowing services existed, not seeing the advantages, needing reasonable adjustments, seeing a named professional, not having laptop or PC, having difficulty getting into the system, not available for under 18s.

The variety of rules, spoken and unspoken around the online systems were apparent too – at one dental surgery you can book online months ahead, at another they won't let you book ahead more than 3 weeks - presumably though not stated to stop slots being fully booked months in advance.

Assistive technology, even that built into laptops and mobile, was rarely recognised as being available. This is interesting given that many family carers use assistive technology daily to support their family members. Again the uses and benefits need to be made clear.

Old age and habits were barriers for older carers accessing services online, in this study and this is in line with national trends. However, family carers all cited relatives in their 70s and 80s who could text and use iPad. They were motivated by social media to stay in touch with family and friends. Yet they all phoned the GP as did their younger counterparts.

Assumptions that an older carer cannot or will not use technology need to be revisited in some cases and similarly the two men interviewed were no more competent than their spouses – according to the spouse! They are held back in part by anxiety, getting it wrong for their family member can have serious and in some cases life threatening consequences.

Knowledge and skills

The knowledge and skills that family carers need to identify and navigate health systems include knowledge of social care, education, employment and benefit systems. Supporting long term conditions and complex needs requires knowledge of the mental capacity act, the care act, the equalities act, the benefits system, social care assessments, continuing health care, out of hours services, emergency services plus the medical conditions and behaviours their family member needs.

Therefore, family carers are able to learn new skills, but have to see why the new service/software/app/programme or website offers good or better care than what they have worked extremely hard to get in place. Websites and Apps which received positive reviews and were complex to use, e.g. WikiMe requires a training course – but family carers were willing to do it because it met their family members' needs.

People who are not first language users

OXFSN support family carers who do not have British English as their first language – those who have come to the UK to live and work and deaf people for whom BSL (British Sign Language) is their first language. An additional barrier for these family carers is having lower levels of literacy, including deaf people. People with learning disabilities then face a double barrier of having a family carer unable to use services on their behalf. Family carers then have an increased responsibility to interpret and/or translate in situations which can compromise the choice and dignity of their family member.

Video remote interpreters and video relay services are available 24/7 for online systems and have the potential to make life easier for deaf people but they have visual limitations for those with sensory impairment. Similarly, translation services are available in a variety of formats and need to be made quickly and easily available on-line. Live translation and interpreting will always be the safest options for some appointments.

COVID-19

The family carers interviewed, have all accessed health services during this time, by phone primarily, followed by email and in one case Zoom consultations. These encounters worked better than expected for family carers whose expectations were low and relief at getting support, was high. For example, less waiting time for phone calls to be answered, conformation texts from GPs in response to emails and prescription requests. This has led to questions like – why could we have done this way before? There is an opportunity to capitalize on this positive experience and to make these changes sustainable.

9. Conclusion

Older family carers 70s+ do not have the confidence, skills and equipment needed to convert to fully online services to support their family members. They will need alternatives to online only services.

Family carers will use online services if they know about them, can quickly and can easily use them. But... they must offer better care than the current arrangement they have worked for years to get in place.

Regardless of age or digital literacy family carers will always seek to reduce the risk by whatever means is possible by ensuring reasonable adjustments are in place. They regard a face to face relationship with a medical professional as paramount to ensuring the quality of care – digital services can enhance but not replace this.

Family carers who are not first language users of British English, face increased barriers when using online services. However, opportunities to improve digital services are growing and embedding interpretation and translation options are already out there.

10.Next steps / recommendation for final LDE report

Other views need to be brought into this conversation to get a fuller picture – suggestions to get started are below.

1. Contact support providers for more information about their views on how this could work well – Style Acre in Oxfordshire come highly recommended for using an app called Nourish where support workers record every detail of the health and well-being of the person they support <https://styleacre.org.uk/>ranging from teeth brushing to medical appointments.
2. OACP for their feedback more generally on issues for care provider organisations- Eddie McDowell is the best contact, <https://oacp.org.uk/>.
3. Contact special schools who use online digital platforms e.g. apps, websites and online booking systems with parents already may have useful information – Tom Proctor-Legg Head teacher at Iffley Academy would be a good starting point. <https://iffleyacademy.co.uk/>.
4. Colleges of FE who run specialist courses for people with learning disabilities using digital platforms. Abingdon and Witney College use WikiMe- to communicate with students and their family carers and support providers. <https://www.abingdon-witney.ac.uk/courses/areas/pathways>

Appendix 1

Table 1: Profile of family carers and their family member

| | <i>Age and Sex</i> | <i>Age and sex</i> | <i>Living situation of family member</i> | <i>Health of family member</i> |
|-----|--------------------|--------------------|--|--------------------------------|
| 1 | A 50s (F) | Teen son | At home | Long-term conditions |
| 2 | B 30s (F) | Child son | At home | Complex needs |
| 3 | C 50s (F) | 20s son | (ATU) | Complex needs |
| 4 | D 50s (F) | 20s daughter | In supported living with 4 others | Long-term conditions |
| 5 | E 50s (M) | teen son | At home | Long-term conditions |
| 6,7 | F 80s (F, M) | 50s daughter | At home | Long-term conditions |
| 8 | G 70s (F) | 40s son | Supported living | Long-term conditions |
| 9 | H 30s (F) | Child son | At home | Complex needs |
| 10 | I 50s (F) | 20s son | Supported living with 3 others | Long-term conditions |
| 11 | J-sibling 18 (F) | teen brother | At home | Long-term conditions |

Table 2: Comprehensive personalised care model based

Source: <https://www.england.nhs.uk/personalisedcare/comprehensive-model-of-personalised-care/>

| Population with access to NHS | Personalised care intervention |
|---|--|
| 5% complex needs- multiple conditions and functional impairments | Specialist intervention: personal health budgets, integrated personal budgets, integrated personal commissioning |
| 30% long term physical and mental health conditions | Targeted interventions, personalised care and support planning and supported self-management |
| 100% whole population | Universal interventions: Social prescribing and community capacity building and shared decision making |

Appendix 2

NHS Digitisation for Personalised Care: Survey for Family Carers

1. Who makes doctors, dental and hospital appointments for your family member? (i.e. you, them, their support worker?)
2. What ICT equipment do **you** own? (e.g. mobile phone, tablet, PC)
3. Do you use any health apps and websites to support your family member? If so, which ones and are they useful? (e.g. Wiki, patient access, NHS websites) What help do **you** need to use this? (e.g. help from kids, partners, friends and professionals, online videos, support groups)
4. Do you currently use any online services related to healthcare (i.e. GP or dental online appointments/ repeat prescriptions)? Do they work well? What would make them better?
5. What assistive technology* do **you** use to help you access digital media?
6. How do you manage passwords and confidentiality and privacy issues for your family member?
7. What skills do you think **you** need to use the apps/ websites that help you manage your family member's health?
8. What knowledge do **you** need to support your family member? (e.g. their medical details, dates of appointments etc.)
9. What worries and/or stops you using new services increasingly coming online? (time, cost, understanding, too clunky)
10. What support do you need to use a new online service? (e.g. letter or phone call explaining new services, online or telephone support, opt out options)