NHS Education for Scotland
Equality Impact Assessment Report

Name of function, policy or programme: Essential Anticipatory Care Plan (EACP)
NES directorate or department: NES Digital Service (NDS)

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1. Define the function

1. The national digital platform (NDP) seeks to enhance health and care services across Scotland by ensuring the right information is available to the right people, in the right way, at the right time.

2. At a time of global COVID-19 pandemic, significant consideration has been given to how digital health solutions can be deployed to support improved interaction between people and healthcare services.

3. NDS has been asked to support conversations about what matters to people with those who have complex needs, including the ‘shielded group’ (extremely high risk and high risk) people during the COVID-19 public health emergency.

4. The specific focus is on:
    - efficiently capturing conversations about future care;
    - sharing information captured in these conversations across the health ecosystem; and
    - ensuring this shared information is referenced when treating a person.

5. The NES Digital Service (NDS) will develop a digital solution to address care co-ordination. It will work in partnership with Healthcare Improvement Scotland (HIS) and Scottish Government to ensure the solution aligns well with wider context work such as supporting severely frail people in a community context.

6. HIS has developed the template upon which the product is based. The Essential ACP guidance and template document provides help for the healthcare professional leading the conversation and the questions to ask.

7. The scope and duration of the product were unclear at the outset given the initial fast-moving developments around COVID-19. Things have stabilised into a clearer set of requirements more recently. HIS has commissioned NDS to develop and host a web form called EACP. The form will capture an individual’s preferences for care. The form will be available on the internet, and therefore, anyone could complete it at any time. However, it

is intended to be used to capture the data during a conversation between a care professional and the individual to whom the data relates.

8. On completion, the person filling out the form has the option to save it to a PDF for storing locally and/or sharing with other relevant people e.g. the individual, the individual’s family, professionals involved in the individual’s care.

9. EACP is hosted within the NDP but does not use any of its shared components. No data is persisted or held by NES. Data will be held in the user’s browser on their device as the user fills out the form, and for converting to a PDF on completion. Once the PDF is saved, any data in the browser is deleted.

10. The function is aimed at addressing information deficits for the most vulnerable and at-risk members of the community at a time of continued uncertainty, where capturing treatment preferences and emergency care wishes could have enormous impact on the system as it begins to restart “business as usual” activity. In particular, the impact of late presentation of mild to moderate symptoms experienced during the lockdown period could present significant systemic challenges.

11. The EACP product is being designed for use initially by care practitioners to assist in recording good conversations with people.

2. Evidence used to inform assessment

1. The focus of evidence gathering has been across three areas: the anticipatory care planning (ACP) process itself, including its current implementation across Scotland; digital inequalities more generally; and the interplay between redesigning health processes – often considered the ambit of health literacy and service design in the healthcare context – and supporting them with digital solutions.

2. In the context of the pandemic, there has been significant debate related to care planning particularly at end of life. Significant concerns were raised by organisations working to protect and promote the rights of older and disabled people. In particular, concerns were raised about approach to DNACPR (do not attempt cardio-pulmonary resuscitation), how conversations on this topic were best handled, and how the information was recorded and communicated. In some ways this had motivated the development of the EACP product and guidance surrounding its proposed use. Scottish Government issued overarching guidance on ethical advice and support. This has been subject to ongoing equalities activity with equalities leads in health boards co-ordinating an impact assessment that will inform future iterations of the ethical advice, but also be useful to incorporate into our thinking for EACP.

3. The ACP approaches – and care planning conversations that more generally have a focus on the question of What Matters to You? – have the potential to open up discussions for people who are vulnerable and ordinarily could be at risk of being excluded from being involved in discussions about their care. They can be an important tool to advocate for people’s needs or wishes, when they may be faced with an emergency situation but not necessarily have an advocate present.

4. To understand the current range of approaches to anticipatory care planning, Healthcare Improvement Scotland led a piece of work in partnership with Scottish Government and NDS where a sample of people, practitioners and organisational representatives were interviewed to capture their views and thoughts. This has positively contributed to the product development, ensuring the application better meets clinical needs and is responsive to a range of digital skill levels.

5. We examined how the application would meet widely understood and adopted accessibility standards. We undertook research on available materials related to digital inequalities. We also examined design approaches that form part of the wider work of NDS and have been a key part of product development.

3. Results from analysis of evidence and engagement

1. Equalities issues have often been poorly considered by digital and technology programmes across the public sector. While there is strong understanding and adherence to equalities legislation and regulation at organisational level, the fragmentation of the approach to technology development – as identified in reports such as the Expert Panel report on digital health and care in Scotland – has led to a lack of clarity on who is responsible for maintaining high standards of accessibility. This is often heightened by a lack of clarity around "ownership" of parts of processes being supported and the products and tools used to support those processes. The NDS approach to bringing greater consistency to digital services for health and social care means it has an excellent opportunity to address this fragmentation and lack of clarity to create conditions where diverse needs are both recognised and met.

2. ACP and collaborative care planning approaches are typically adopted to support people with long term conditions (and often a complex interplay of conditions) to best integrate ways of living with those conditions into their everyday lives. At its heart is a "balanced conversation between experts" where the expertise that a person brings to managing their own conditions is given equal validity to clinical or practitioner perspectives.

3. These types of approaches are often rooted in a drive to make access to healthcare more equitable, with processes – ReSPECT being a good example – often subject to careful and rigorous design activity aimed at meeting diverse needs.

4. During the current pandemic period, those people who are most at risk of serious severe illness from COVID-19 are drawn from groups that will have greater or lesser familiarity with care planning approaches. Those living with respiratory conditions such as chronic obstructive pulmonary disease (COPD) or a rare metabolic disease may have care planning well-embedded in their thinking. Those with compromised immune systems or having continuing antibody treatments might be rather less so.

5. A common thread for all, though, will be elevated need for consideration of what living with your conditions looks like as the current pandemic moves to restart, readjust and reboot phase. In particular, the need to build clearer understanding across the population on the impact of particular behaviours as we move beyond population-level "everyone stay at home" advice, to more nuanced advice linked to risks and mitigations is vital. Careful consideration needs given to the role that collaborative conversations such as those that are central to the ACP process could play.

6. When documenting equality impacts of a given policy, particularly one with as potentially wide-ranging applicability as care planning, it is important to consider things from a breadth of perspectives. We have an obligation to

consider things from viewpoint of protected groups. We know there are also a range of cross-cutting factors that go beyond these groups. We have structured evidence of those issues under an emerging “barriers to access” framework, which sets out challenges from the perspective of the motivations that drive people to engage or not with particular activities.

Protected characteristics

7. Equalities impact for the following protected groups was considered as part of the EACP development:
    - age
    - disability (for example ongoing respiratory conditions)
    - gender reassignment
    - marriage and civil partnership
    - pregnancy and maternity
    - race
    - religion or belief
    - sex
    - sexual orientation

8. While the breadth of the work could impact across most or all of these groups, we looked in detail at **age, disability, race** and **religion.**

9. In terms of **age**, older people within the general population and more specifically the shielding population may experience particular issues. These may include:
    - lower levels of digital enablement, with fewer people likely to have access to and/or be proficient in the use of technologies which could support them;
    - frailty may lead to lower engagement with the programme due to poorer health and greater sensitivity to stressors;
    - there may also be practical issues around participating. These may relate to things like access to technology with collaborative conversations likely to take place over video call during the current period. But they may relate to other issues – explored in more detail in the next section – related to motivations and willingness to participate.
    - maintaining physical and social distancing during the pandemic period may have strong impacts for older people. Aside from the effects of isolation on mental health, practical challenges of daily living – food preparation for example – may have an impact on physical wellbeing. Priorities and preferences around What Matters to You are likely to be impacted by the current constraints on movement and interaction with the community.

10. In terms of **disability** people could experience a number of barriers to engaging with care planning conversations. These could include:

    - information in inaccessible formats or languages. Various accessible formats need to be considered, including plain English, easy read, coloured background (dyslexia), braille, image-driven approaches, BSL and clear verbal communications or tactile communications.

- people with dementia and with neuro-diverse conditions such as autism may feel distressed around the style and format of conversations. Accommodating these concerns has an applicability to all cases, recognising that healthcare interactions are often intrinsically stressful or anxiety-inducing. Effort needs to be focussed on preparing all people in advance of a care planning conversation, to put them at their ease as far as possible. Only then can people and practitioners best contribute. Thought should be given to advocacy or supporting mechanisms to ensure people can best cope with what might be an unfamiliar approach.
- During the pandemic period, concerns were raised around care planning conversations, particularly in the context of end of life care. The debate focussed on factors such as coercion in discussions about resuscitation (specifically cardio-pulmonary resuscitation), whether human rights were being respected, and whether there was a sense of disabled people's lives being undervalued. These were major factors in the recommendation from the iHub service design work to engage in a public debate and awareness raising campaign about care planning, the aim of which would be to promote trust through better understanding people's perspectives on these complex issues and developing solutions that were responsive to them and promoted greater trust.
- Again, issues relating to shielding and isolation may create increased practical barriers to supporting everyday health and wellbeing.

11. In terms of **race** people of black, Asian and minority ethnic (BAME) backgrounds may experience particular barriers:
    - racially aggravated hate crime is the most frequently recorded category of hate crime in Scotland. Therefore, with people already experiencing the impacts of isolation, further reluctance to engage in healthcare could develop.
    - culturally diverse dietary needs may have been impacted by the current social isolation. This links back the points previously made about the practical challenges to maintaining good physical and mental wellbeing being heightened during the pandemic period.
    - There may be a greater number of people for whom English is not a first language. They may therefore be unable to understand any information provided or engage fully in collaborative conversations if services are not designed to be responsive to those needs.

- Black and minority ethnic people are more likely to live in poverty and therefore the issues around digital access noted above could also apply.
- There is emerging evidence of much greater impact of COVID-19 in terms of infection and mortality in BAME populations. This will have a correlation to socioeconomic factors alluded to above, but we will need to monitor further evidence for additional impacts. It further emphasises the need to design the care planning approach and the processes that sit around it to meet a diverse set of needs.

12. While **religious belief** plays a strong role in general attitudes to health and care and specifically to perceptions to death and end of life care – often a strand of work with a close association to anticipatory care planning – it is less clear that digital approaches to support this area of practice have a significant positive or negative impact. We know that religious views often have to be considered sensitively during collaborative conversations. We need to ensure that this aspect is handled in a highly responsive and sensitive way.

Service design

13. A service design approach – aligned with the Scottish Approach to Service Design – has been adopted across NDS. This ensures inclusive, user-centred approaches to involving those directly impacted upon by the implementation of the new product in its design and delivery. It also helps our continuing work to mitigate against the potential for digital to widen health inequalities is a key element of wider equalities activity across NDS products.

14. But additional recently published research suggests that even when careful and inclusive design approaches are taken, there is still potential for significant challenges, particularly with elderly and ageing populations.

15. At the start of the development of the EACP product a report completed by the Healthcare Improvement Scotland iHub in collaboration with NDS and the Scottish Government set out key findings from a focussed piece of user research in relation to collaborative conversations, particularly in the current pandemic period. This work has significantly influenced our thinking. This is briefly summarised in Annex A.

16. Doteveryone’s Consequence Scanning approach initially informed our consideration of equalities issues and how to embed thinking into everyday agile processes.

17. Since then, work in this sphere has developed as the NDS approach to service design has progressed. As part of that, the following challenges have been formulated relating to what may influence whether people engage with health-related activities. These reflect ongoing discussions

with the Government Digital Service on this and other topics. These barriers have been identified to help wider considerations about the needs of those interacting with the NDP. They include:

- Enthusiasm
- Emotional states
- Awareness
- Self-confidence
- Access
- Comprehension skills
- Interface & interaction skills
- Trust
- Time
- Evidence
- Finance

19. These have some resonance with the domains of digital inclusion outlined in the New Zealand government's blueprint which articulates them both as barriers and areas for action.

Barriers

20. In terms of **enthusiasm**, people could experience a number of barriers to engaging with care planning conversations:

- The engagement and enthusiasm levels of people and practitioners fundamentally needs to shape the level and pace of care conversations.
- People who are more engaged with their healthcare, understand their likely clinical pathway and are motivated to self-manage, often have a greater understanding of the benefits of proactive approaches. It would be anticipated in these instances, that people would recognise the benefits to care planning conversations and be more willing to engage in these conversations.
- By extension, people with less understanding of their health situation, may be less likely to realise the relevance of collaborative conversations and shared decision making. This creates an opportunity to include guidance around good conversations at point of diagnosis or when a condition emerges.
- Although the term is sometimes viewed as problematic, there is research and practice around a concept called patient activation. This is understood to be the knowledge, skills and confidence a person has to manage their own health and health care, so has a strong coherence with health literacy, but has a focus in the domain of enthusiasm. It is a stronger predictor of health outcomes than socio-demographic factors alone such as age and ethnicity.
- A 2014 report from The King's Fund, highlighted patient activation as a mechanism to address health inequalities beyond traditional socio-demographic factors, and consider tailored support to those least engaged. This correlates with helping those furthest behind, as

articulated by the World Health Organization, and described in Tudor Hart's Inverse Care Law.
- The importance of What Matters to You? as the starting question for collaborative conversations is clear. This has been embraced in settings such as medications reviews and is increasingly a cornerstone of anticipatory care planning. The need for open and collaborative approaches to engagement to enable future care planning conversations should remain a focus.

21. In terms of **emotional state**, people could experience barriers to engaging with care planning conversations:
    - During the current pandemic period, it is likely that those with significant long-term health conditions – and this may be experienced in more severe ways for those identified as part of the "shielding" group – will feel very isolated due to the lack of social and health care interactions and anxieties around COVID-19 infection risk.
    - While everyone is different, it should be expected that the emotional challenges this brings may mean that people feel less resilient to have conversations considering issues such actions to be taken at points of potential deteriorations in health. However, we know from initial evidence from a survey of the shielding group that 70% of people have reported they are coping OK with staying at home during the current phase.
    - It is reported that people shielding, welcomed the opportunity to discuss their health concerns and future planning with GPs when they phoned.
    - Mental health is an area of particular concern, as isolation is a recognised contributor to decreased mental health wellbeing and resilience. Set against the figure of 70% of people feeling they are coping OK with shielding is the fact that 76% of people reported a negative impact on their mental health. The move of mental health support services to an online/digital/telephone options will be a sizeable shift for those previously accessing face to face support.
    - Third sector organisations such as Scottish Huntington's Association, are providing online and telephone support such as 'virtual hubs' to support the various mental health, financial, caring responsibilities and other challenges in the current situation. Evaluations of these services will be important to track any shifts in preference for service delivery channels.
    - Evidence from previous pandemics such as the 2001 UK foot and mouth disease epidemic, highlight the challenges public health emergencies put on mental health and people's ability to cope with the uncertainties associated.

22. In terms of **awareness**:
    - As with enthusiasm, people who are more engaged with their healthcare, understand their likely clinical pathway and are motivated to self-manage, often have a greater understanding of the benefits of proactive approaches. This links to inequalities of access along the lines of the Inverse Care Law – those that can access, will and do access – so there's a need to ensure that a broad and diverse range of people are aware of the benefits of anticipatory care planning approaches.
    - In the current pandemic period, work has been undertaken to promote the benefits of collaborative care planning conversations to consider future care wishes. A report completed by the Healthcare Improvement Scotland iHub recommended a national awareness raising campaign delivered by trusted figures. This would have the aim of building a clearer understanding across the general population, both in terms of COVID-19 as population-wide public health emergency and for those at highest risk of severe impact if they were to become infected.
    - A key builder of awareness is community connection and word of mouth. At a time when the whole population has been isolating and routine health and care services have been paused or reduced, many will have limited interactions with their usual healthcare professional such as their GP. Those isolating may have either limited carer support or no-one interacting with them in their homely settings. Effort needs to be focused on ensuring people who are isolating are connected to those important to them. This has been an increasing motivator for the use of digital solutions such as online remote consultations (Attend Anywhere, NHS Near Me etc) but phone and SMS services have played an important role, as well.
    - Changes in messaging and health advice, as the pandemic moves through different phases is an area for particular attention. Once messages move beyond short, sharp population-level slogans such as "Stay Home", conveying effective, tailored advice becomes more complex. As new research and evidence emerges, understanding of the interaction of multiple health conditions and factors relating to vulnerability to COVID-19 in different populations will change the guidance people are given. Efforts need to be redoubled to ensure everyone receives clear communication explaining any changes of guidance, what this means to the individual, and what actions need to be taken.
    - Awareness of the personal risks and benefits arising from changes in advice and behaviours, should be addressed and supported in collaborative conversations. Anticipatory care planning approaches may provide one of the key vehicles for these conversations.

23. **Self-confidence**, or the lack of it, may be a barrier to engaging in care conversations. This has many facets to it, some of which have been emphasised during the current pandemic period:
    - A decline in self-confidence and self-belief may correlate to lower resilience to uncertainty. Reduced mental and physical health as

indirect consequences of shielding and the associated social isolation would be expected to lead to people experiencing lower self-confidence.

- Employment and financial uncertainty may impact self confidence and self-esteem. This is a major concern at the current time for many people. Younger people shielding may have significant concerns around continuing engagement with education or employment. The immediate and longer-term financial effects may affect their self-belief and self-esteem.
- Disability, physical and mental health conditions, particularly long-term ones, can have a range of positive and negative impacts on self-esteem. These alone, aside from social isolation and anxieties, are significant factors in people's self-belief to understand complex and sensitive subjects, such as future treatment preferences.
- Care planning conversations often consider speculative health situations. The unknown elements of these conversations, combined with potentially sensitive emotional state and reduced resilience, may be challenging for people. Attention should be paid to what support mechanisms (family, carers, third sector and voluntary organisations) someone has, together with their level of engagement in understanding and managing their health.
- Advocacy could be a useful concept and service to think about to promote people's self-confidence. Often interactions with healthcare services are perceived as required to be 'one-to-one' conversations, but there's no reason why that should always be the case. There are often strong reasons to involve others to promote confidence and understanding. It is also often vital for families and carers to be a part of the ongoing dialogue about a person's preferences and wishes for future care.

24. **Access** covers many aspects and is both sweeping and nuanced:
    - Barriers may arise in terms of access to healthcare services, access to relevant equipment, access to digital infrastructure and services, access to support that in turn supports access (for example library services that promote access to health information), and then the accessibility of the information associated with all of these aspects.
    - In terms of the digital aspects, much of the existing evidence in relation to digital equalities relates strongly to socio-economic factors – income, status, access to technology devices such as smartphones etc – and location-based factors – network coverage in remote/rural areas (and for ambulances in transit), broadband availability, service accessibility – and digital skills and usage, such as the Office of National Statistics figures outlined above.
    - It has been an important part of the development of the EACP product to ensure that the user interface efficiently supports clinicians. This has led to careful consideration of how information is presented, with an accessibility audit revealing key areas that were addressed in product development. In addition, wider design standards from the Government Digital Service and the NHS digital service manual have been adopted

to ensure clarity and consistency of experience, as well as the high-quality accessibility.

- Such service improvements are part of wider health system improvement goals, as a recent European Commission paper on Digital Transformation says:

  > "Attainment of the broad health system goals, including quality, accessibility, efficiency and equity, are objectives against which to judge new digital health services. These goals are unaltered by the process of digitalisation."

- However, it seems unlikely that 'unaltered' is the correct formulation, as there is emerging evidence of greater complexity to consider.
- The interplay between digital and health inequalities has been identified as both a potential solution, but often a potential problem for health inequalities. Meta-analyses such as Latulippe et al are clear that many previous digital health solutions have contributed to the widening of the divide between those at risk of social health inequalities and the rest of the population.
- Recently published research (November 2019) by Azzopardi-Muscat and Sorensen is stronger in cautioning digital transformation programmes to address the issue of health inequality directly in their design. This needs to be in place to stem the flow of exacerbations of inequalities that most digital transformations have brought, particularly associated with increased age, lower level of educational attainment and lower socio-economic status.
- This highlights that this area is likely more nuanced than to say that health system goals are unaltered by the process of digitisation. Given the context of the Fairer Scotland Duty, which places a legal responsibility on public bodies in Scotland to actively consider how they can reduce inequalities of outcome caused by socioeconomic disadvantage, this will be a key consideration for the wider work of NDS.
- Access to service issues (including but also beyond the **awareness** issues highlighted above) along the lines of Tudor Hart's Inverse Care Law might need further exploration. Collaborative care plans are often instrumental in prolonging life or maintaining wellbeing, depending on people's preference, so there may be inherent access issues for the wider health system to explore and understand.
- In the current pandemic period, the move towards remote/virtual appointments and the challenges of initiating these, may be a barrier to those who would otherwise proactively seek face to face interactions. The positive experiences of digital solutions such as Zoom as part of more widespread day-to-day interactions may prove to be a catalyst for wider adoption of technology, particularly for those people and communities that have not felt engaged or motivated to use these tools previously. The work on Connecting Scotland will also offer a range of positive experiences to build upon.

25. **Comprehension skills** are another potential barrier to consider:

- The ability to fully understand spoken advice or written content is fundamental, but we know that there are widespread difficulties. Health

literacy statistics are stark on the subject – 43% of people struggling with basic written dosage information rising to 61% when numbers and calculation are included. So this is a population level issue with the burden firmly on the health and care system to make itself more understandable and accessible, in line with Scotland's health literacy action plan.
- The work of NDS will take a health literacy responsive approach. This is in line with the New Scots strategy on refugee integration, as well as the wider health literacy action plan.
- There is a requirement for accessible information formats such as plain English, easy read, high-contrast backgrounds (for people with dyslexia), braille, image-driven approaches, BSL and clear verbal or tactile communications.
- Any digital solution forms part of a spectrum of different formats offered to support the conversation, based on people's preferences.
- Translation services may need to be organised ahead of a clinician's care planning conversation with the citizen. Time may be needed between the clinician and translator to discuss the sensitivities of the proposed conversation in advance, to ensure clarity of communication and nuances that may be difficult to translate.
- It is reported that over half of BSL users rely on friends and family to interpret for them during healthcare appointments. BSL interpreters may be needed where these conversations take place in situations such as where the citizen can't see the face of the clinician. In the current pandemic period, this be due constraints on signal quality where remote consultations are taking place or due to face masks being worn.

26. **Interface and interactions skills** may be experienced as barriers to care planning conversations. These could include:
    - Lack of digital skills. A recent NHS Digital report into widening digital participation highlighted the most frequent users of the NHS also most likely to be socially as well as digitally excluded. Digital exclusion risks exacerbating existing health inequalities.
    - One in five adults lack basic digital skills, with age and disability identified in the same report as being the protected characteristic groups disadvantaged most by digital services.
    - A recent SCVO report identified the most common reason for not using the internet is a lack of confidence, motivation or understanding. Action is needed to ensure the move to digital services enables participation for all, not widening these well-known inequalities or creating further barriers to care planning conversations.
    - People with Parkinson's Disease, dementia, neuro-diverse conditions such as autism and Huntington's Disease, may find verbal interaction a barrier to collaborative conversations. Mitigations are required to ensure that the needs of this wide group of conditions are supported to ensure full participation in care planning conversations. Again, advocacy, carer involvement, or simply having another person involved in the ongoing conversations should be considered and promoted as approaches.

- Collaborative conversations need to be conducted bearing in mind the citizen’s ability to understand the subject and also allow them to be able to communicate back to the GP/clinician. For example, non-verbal citizens may be able to communicate via email, a range of assistive communications tools, or handwriting, but if conversations are remote online or by phone rather than face-to-face there needs to be mitigations to allow sharing of their thoughts and wishes with the clinician.
- In some instances and stages of conditions, some citizens may not be able to advocate for themselves while at others times they may be well placed to cope. This variation in ability to interact needs to be supported.
- 16% of people age 60-79 use the internet for managing physical and mental health conditions. Digital engagement is highest in younger adults, with this engagement declining with age.
- For age, a recent Office of National Statistics report says that 47% of adults aged 75 years and over were recent internet users, set against 95% of adults aged 16 to 74 years. This highlights a fact that lower digital usage is linked to increasing age.
- In terms of disability, the same report says that the number of disabled adults who were recent internet users reached over 10 million for the first time. This represents 78% of disabled adults. We need to factor-in how well represented people living with conditions such as dementia are in disability adult statistics. This may reflect a much lower percentage than that quoted in this study. In addition, as statistics emerge from various initiatives supporting citizen access to health information and services, these may provide more accurate and/or relevant evidence.

27. When considering **trust** and collaborative relationships, four of the most common elements needed to develop trust are **competence, reliability, integrity and communication**. These have a complex interplay and without any one of these, it can be difficult to create the trust needed for a sustainable trust relationship. People may experience a number of trust barriers to engaging with care planning conversations such as:
    - Trust is central to citizen-clinician relationships. It is understood to influence adherence to treatment, perceptions of clinician’s motivations, cooperation with a healthcare system. Healthcare system experience has been shown to affect public trust in wider authorities.
    - Trust of healthcare practitioners goes beyond building rapport. Maintenance of trust, often delivered through continuity of care practitioners involved in particular cases, and the boundaries and limits of what the clinician can deliver, need to be clearly communicated.
    - Mistrust of the unfamiliar, such as unfamiliar people and situations. For example, in a hospital setting when health has deteriorated. Collaborative conversations with a clinician relatively unknown to the citizen, and in the absence of family or other advocates, may be viewed with fear, uncertainty and doubt.
    - Lack of awareness or understanding of how the conversation information will be used and by whom can also be a barrier. These

concerns should be addressed before care conversations take place. Explanation of conversation information being recorded either on paper or digitally, together with discussion of the instances and health care professionals who would access the care plan is essential. It may be helpful to routinely providing the citizen with a printed copy of the EACP to keep at home to build the confidence needed to ensure these conversations are as meaningful as possible.

- As part of this, there is a need to be clear that people can (and will) change their mind about their care plans and wishes.
- There may be a need to develop a sense of "restorative trust" to address previous negative experiences of a health deterioration point or healthcare service engagement.

28. In terms of **time**, people may experience barriers such as:
    - Collaborative conversations can take more time at the start of the process but result in greater efficiency and improved experience longer term. But the initial time barrier is a relevant consideration for both people and practitioners.
    - In turn, more than one collaborative care conversation may (and almost always will) be needed. People may wish to think about their care wishes and discuss these with family before finalising care plans with their practitioner. Consideration should be given to advocacy or supporting mechanisms to ensure people can best contribute to these conversations. But again, there is a duration and effort needed, from all perspectives, and it's important to be clear about this.
    - Health literacy inequalities may mean that some people don't fully understand various aspects the conversation with their practitioner, but don't express their lack of understanding. This further emphasises the importance of health literacy good conversation practices, but also means that time could and should be allowed for confirmation and re-confirmation of information and decisions.
    - During the current pandemic period, increased practical barriers to supporting everyday health and wellbeing may arise as a result of shielding and isolation. This may limit time available for other health supporting activities such as gathering information or spending time on phone calls to understand information.
    - Current lockdown advice may limit positive health behaviours such as regular exercise to very specific time-windows resulting in diminished control of conditions best managed in this way. In particular, the impact on mental health should be considered.

29. In terms of **evidence**, this barrier could be experienced in a number of ways:
    - It is possible that people may be uncertain about the evidence of the effectiveness of collaborative care conversations, but in contexts where existing care planning processes are well embedded this is less likely to be an issue.
    - During the current pandemic period, the question of evidence is somewhat less clear, particularly given the fast-moving pace at which new evidence is emerging.

- In terms of how the current “shielding” group has been defined, there is evidence that this may not include everyone who is or considers themselves at highest risk. The list of those shielding is likely to change over time. There is a need to be clear on how needs are being prioritised to reduce the stressors of these engagements.
- There was a clear sense from a survey by Inclusion Scotland that the root of people’s concerns around shielding (and related issues such as perceptions of coercion related to resuscitation decisions) was a lack of engagement. “We’re at risk from the actions of public bodies and others who don’t understand who we are, what we need or what will work. Why? Because they haven’t asked us,” is a particularly pertinent quote. This needs to be addressed by a more open and inclusive approach to design.
- Differences in public and policymakers’ understanding of the wide range of disabilities, sensory impairments and numerous health conditions leading to the need to shield or isolate have resulted in situations such as blind and partially sighted people being unable to access priority supermarket deliveries.
- From a different perspective on the term “evidence”, a barrier is often created where people are asked to provide or assert types of evidence – ‘upload a picture’, ‘submit an online form’, or even ‘register with an email address’ – where different approaches could be taken to gain access to services.

30. In terms of **finance**, people may experience barriers such as:
    - Additional costs accessing information and services. This could include device and infrastructure barriers to engaging digitally or online.
    - There may be costs for people in recommended treatments, particularly where they relate to diet and exercise. There may be a lack of access to the most economical resources, particularly in remote and rural settings, such food deliveries.
    - In the current pandemic period, consideration has and continues to be given to ensuring services such as the SMS Shielding Service, use the most economical/least data costly means.
    - As the guidance on shielding and managing conditions becomes more nuanced, there may be pressure for those initially isolating, to return to work earlier than they feel appropriate. Impact on income, benefits and other financial support, requires elevated consideration to avoid both anxiety and economic-induced stressors.

4. Actions taken or planned in response to issues identified in the analysis

Issue identified	Action to be taken in response to issue	Responsibility	Timescale (indicate whether actions have already been completed, or provide timescale for carrying out the action)	Resources required	What is the expected outcome?
Need to ensure accessibility standards met	Accessibility audit undertaken, with action plan documented and implemented	EACP development team	September 2020	Development time – factored into product management	Product fully meets accessibility standards
Need to embed equality and diversity thinking into agile product management practices	"Barriers to access" approach adopted into design and development processes	EACP product manager	ONGOING – initiated in June 2020 as a continuous improvement practice	Continued refinement of approach in collaboration with Government Digital Service (GDS)	Equality considerations become an everyday part of NDS product development
Need to consider the wider issues of how digital solutions and health inequalities interact – particularly the	Continued interactions with the NHS Scotland, local government and third sector equality & diversity networks to collaboratively	NDS team	ONGOING – initiated in June 2020 as a continuous improvement practice	Time identified within NDS staff roles to progress the work; supporting resources will need scoped	An approach to embedding equalities thinking across all NDS work is developed and implemented

impact of wider socio-economic factors on care planning – to guard against a ‘double inequality’	and continuously co-design the wider NDS approach to equalities				
The user interface of the EACP digital solution presents problems for clinicians in safely recording information	Government Digital Service (GDS) standards adopted; full accessibility review undertaken	NDS team	September 2020	Development time – factored into product management	Product fully meets accessibility standards

5. Risk Management

1. In this assessment, have you identified any equality and diversity related risks which require ongoing management? If so, please attach a risk register identifying the risks and arrangements for managing the risks.

2. High-level risks and mitigations have been identified, summarised below:

    - The EACP application fails to meet user needs due to accessibility issues.
      Mitigation – accessible design principles adopted into application development.
      Mitigation – actions from accessibility review implemented

    - Users of the EACP application do not have the required digital skills to use the application
      Mitigation – user-focussed design principles adopted into application development.
      Mitigation – digital skills of users assessed with training and support made available to all to ensure equity of access.

    - The digital solution to support EACP undermines current positive experiences around the implementation of ACP processes
      Mitigation – user-focussed design principles adopted into application development in collaboration with the practitioner teams

    - The user interface of the EACP digital solution presents problems for clinicians in safely recording information
      Mitigation – product developed to design and accessibility standards
      Mitigation – ongoing approach to development and refinement of the EACP product, based on user feedback

    - Equality or health inequality issues are exacerbated by the implementation of the EACP application
      Mitigation – ‘barriers to access’ approach adopted into application development.
      Mitigation – consider more detailed research work on this topic, working with clinical colleagues.

6. Consideration of Alternatives and Implementation

1. The accessibility review led to changes to the coding of the EACP application. With these changes made, no additional alternatives or changes to the proposed implementation were identified.

2. ACP is currently running as a paper-based process – prior to implementation of the digital product – so will continue to be available in this way, based on people’s preferences.

7. Monitoring and Review

1. This EQIA for EACP builds on the ReSPECT EQIA. It is a continuing part of the documented output from NDS' wider programme of equalities activity. It sits as part of the NDS compliance approach, which documents various aspects of impact activity (clinical safety review, data protection impact assessment, system security protocol etc) to ensure that NDS products meet a series of quality criteria.

2. Both the compliance and equalities strands are ongoing parts of NDS activity, with continuous improvement, regular monitoring and review a core part of the work.

3. In terms of data, the initial approach to collection will focus on the qualitative experience of implementation with clinical teams involved.

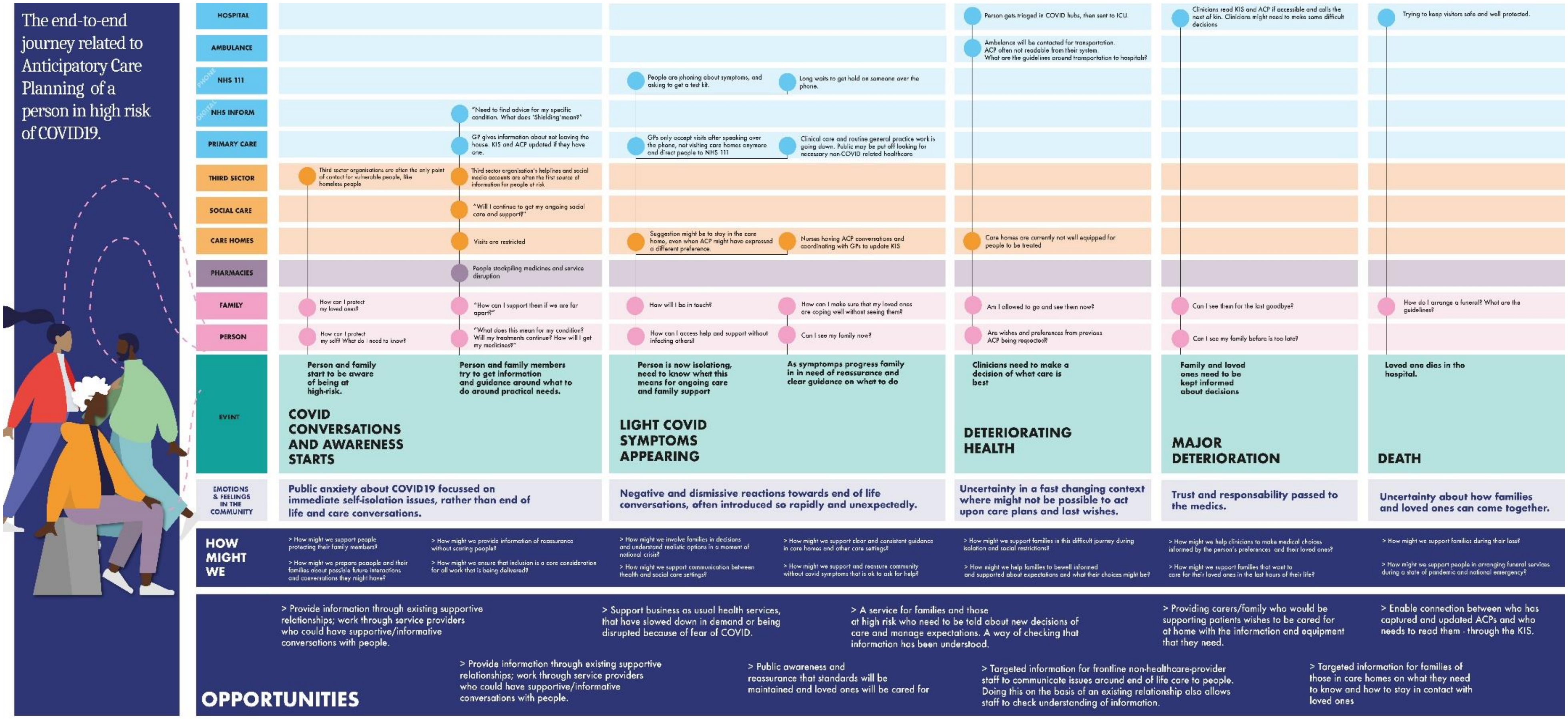
4. Incrementally, quantitative measures will be considered for adoption. These will include the development of commonly agreed metrics around uptake and diversity of those using the ACP process.

5. Continuous monitoring against standards (such as accessibility) will be undertaken as part the product release strategy. In terms of roles and responsibilities for ongoing review, there will be input from the NDS compliance manager, the EACP product manager, and the NDS equalities team.

Sign off (by accountable director):

Geoff Huggins
October 2020

Annex A – output from iHub user research work (further details available from https://ihub.scot/improvement-programmes/living-well-in-communities/anticipatory-care-planning/covid-19-anticipatory-care-planning/)



The end-to-end journey related to Anticipatory Care Planning of a person in high risk of COVID19.

HOSPITAL			Person gets triaged in COVID hubs, then sent to ICU.	Clinicians read KIS and ACP if accessible and calls the next of kin. Clinicians might need to make some difficult decisions	Trying to keep visitors safe and well protected.
AMBULANCE			Ambulance will be contacted for transportation. ACP often not readable from their system. What are the guidelines around transportation to hospitals?		
NHS 111		People are phoning about symptoms, and asking to get a test kit. Long waits to get hold on someone over the phone.			
NHS INFORM	"Need to find advice for my specific condition. What does 'Shielding' mean?"				
PRIMARY CARE	GP gives information about not leaving the house. KIS and ACP updated if they have one.	GPs only accept visits after speaking over the phone, not visiting care homes anymore and direct people to NHS 111 Clinical care and routine general practice work is going down. Public may be put off looking for necessary non-COVID related healthcare			
THIRD SECTOR	Third sector organisations are often the only point of contact for vulnerable people, like homeless people Third sector organisation's helplines and social media accounts are often the first source of information for people at risk				
SOCIAL CARE	"Will I continue to get my ongoing social care and support?"				
CARE HOMES	Visits are restricted	Suggestion might be to stay in the care home, even when ACP might have expressed a different preference. Nurses having ACP conversations and coordinating with GPs to update KIS	Care homes are currently not well equipped for people to be treated		
PHARMACIES	People stockpiling medicines and service disruption				
FAMILY	How can I protect my loved ones? "How can I support them if we are far apart?"	How will I be in touch? How can I make sure that my loved ones are coping well without seeing them?	Am I allowed to go and see them now?	Can I see them for the last goodbye?	How do I arrange a funeral? What are the guidelines?
PERSON	How can I protect my self? What do I need to know? "What does this mean for my condition? Will my treatments continue? How will I get my medicines?"	How can I access help and support without infecting others? Can I see my family now?	Are wishes and preferences from previous ACP being respected?	Can I see my family before is too late?	
EVENT	**Person and family start to be aware of being at high-risk.** **Person and family members try to get information and guidance around what to do around practical needs.** **COVID CONVERSATIONS AND AWARENESS STARTS**	**Person is now isolationg, need to know what this means for ongoing care and family support** **As symptomps progress family in in need of reassurance and clear guidance on what to do** **LIGHT COVID SYMPTOMS APPEARING**	**Clinicians need to make a decision of what care is best** **DETERIORATING HEALTH**	**Family and loved ones need to be kept informed about decisions** **MAJOR DETERIORATION**	**Loved one dies in the hospital.** **DEATH**
EMOTIONS & FEELINGS IN THE COMMUNITY	**Public anxiety about COVID19 focussed on immediate self-isolation issues, rather than end of life and care conversations.**	**Negative and dismissive reactions towards end of life conversations, often introduced so rapidly and unexpectedly.**	**Uncertainty in a fast changing context where might not be possible to act upon care plans and last wishes.**	**Trust and responsability passed to the medics.**	**Uncertainty about how families and loved ones can come together.**
HOW MIGHT WE	> How might we support people protecting their family members? > How might we prepare peaople and their families about possible future interactions and conversations they might have? > How might we provide information of reassurance without scaring people? > How might we ensure that inclusion is a core consideration for all work that is being delivered?	> How might we involve families in decisions and understand realistic options in a moment of national crisis? > How might we support communication between theath and social care settings? > How might we support clear and consistent guidance in care homes and other care settings? > How might we support and reassure community without covid symptoms that is ok to ask for help?	> How might we support families in this difficult journey during isolation and social restrictions? > How might we help families to bewell informed and supported about expectations and what their choices might be?	> How might we help clinicians to make medical choices informed by the person's preferences and their loved ones? > How might we support families that want to care for their loved ones in the last hours of their life?	> How might we support families during their loss? > How might we support people in arranging funeral services during a state of pandemic and national emergency?

OPPORTUNITIES

> Provide information through existing supportive relationships; work through service providers who could have supportive/informative conversations with people.

> Support business as usual health services, that have slowed down in demand or being disrupted because of fear of COVID.

> A service for families and those at high risk who need to be told about new decisions of care and manage expectations. A way of checking that information has been understood.

> Providing carers/family who would be supporting patients wishes to be cared for at home with the information and equipment that they need.

> Enable connection between who has captured and updated ACPs and who needs to read them - through the KIS.

> Provide information through existing supportive relationships; work through service providers who could have supportive/informative conversations with people.

> Public awareness and reassurance that standards will be maintained and loved ones will be cared for

> Targeted information for frontline non-healthcare-provider staff to communicate issues around end of life care to people. Doing this on the basis of an existing relationship also allows staff to check understanding of information.

> Targeted information for families of those in care homes on what they need to know and how to stay in contact with loved ones