Reducing Health Inequalities for People Living with Frailty
A resource for commissioners, service providers and health, care and support staff

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Friends, Families and Travellers
6th October 2020

Acknowledgements

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Executive summary

In response to inconsistencies in the delivery of healthcare services to specific groups experiencing premature frailty, the Department of Health and Social Care, NHS England and NHS Improvement, and Public Health England commissioned the project 'Reducing Health Inequalities for People Living with Frailty". The aim of this project is to share how services have successfully overcome barriers to healthcare for people experiencing health inequalities.

This guide outlines perspectives from patients experiencing inequalities on where the greatest issues in access and outcomes are in relation to frailty, as well as ways in which these can be overcome. Our hope is that this resource will inspire readers to work collaboratively to reach out to underrepresented groups, make services more accessible to those with the greatest needs, and to promote healthy ageing for all.

In our focus groups, we heard that previous negative experiences of services meant that many of the patients worst affected by health inequalities had lost trust in the health and care system. We also heard countless examples of NHS providers and voluntary sector organisations who have been working in innovative and impressive ways to rebuild trusting relationships with disenfranchised patients. We hope that these will inspire you as they have inspired us.

Within this resource, we detail how a shift from an aged-based to a needs-based approach in identifying and treating frailty could provide welcome opportunities for early interventions in populations experiencing frailty earlier in life. We also set out a vision for a place-based approach to support early intervention, prevention and management of frailty, with services working with local communities to address the wider determinants of health, reduce isolation, and build resilience.

At present, groups experiencing disadvantage and exclusion may be missed by efforts to identify frailty. We highlight that there is need to develop a broad, shared understanding of the condition, with greater awareness of the socioeconomic factors that lead to the onset of frailty earlier in life. To ensure these efforts reach groups often underrepresented by services, we highlight that there is need to move beyond an open door approach, and offer services tailored to the needs and priorities of the communities they serve.

Our focus group discussions provided key insight into the challenges many disadvantaged communities face when accessing care services. Participants described experiences of being wrongfully turned away from services, and reported communication issues and practical barriers that made care inaccessible. We highlight that ensuring diverse voices play a role in shaping decision-making can support the development of welcoming and inclusive services. We also outline some simple, practical steps that can help services to overcome barriers to ensure that disadvantaged people living with frailty are able to benefit from early intervention.

Many participants in this project are living with multiple long-term conditions and report complex care schedules. We highlight that addressing multiple needs holistically can support patients to navigate the health and care system, and make care schedules more manageable. To build on this, we demonstrate the value of working with charities and community groups to develop tailored and inclusive education programs to support self-management of conditions. Ensuring that this approach is asset based and patient-centred will assist disadvantaged groups to access support that builds their skills, knowledge and confidence to manage frailty long-term.

Set within the context of relevant research, this practical resource offers guidance to commissioners, service providers, and health care and support staff, to work in a collaborative, holistic and inclusive way to reduce inequalities around frailty. We hope that you will find this useful in your everyday work.

Key themes and recommendations

Our discussions with participants highlighted a number of key themes for health and care services, from which we have established recommendations for commissioners, service providers, and health care and support staff.

Chapter 1. Why are certain groups at high risk of developing frailty and what can we do to address this?

We can

- Take a needs-based, rather than age-based approach to frailty, to support people living with the condition earlier in life

- Work together to offer support and signposting to address the wider determinants of frailty

- Invest in local communities to build social networks and resilience

How can we do this?

1. Service providers can design services around a needs-based rather than age-based approach, using the World Health Organisation's definition of "functional ability"

2. Local commissioners can ensure that the range of support available to people through social prescribing meets the needs of populations at the greatest risk of poor health

3. Local systems can invest in and work with charities, advocacy and advice services, and community groups to support with issues across the wider determinants of health

4. Local commissioners can support community pharmacy to identify people at particularly high risk of social isolation and poor health and signpost to relevant services

Chapter 2. Why are current efforts at identifying frailty missing these groups and what can we do to address this?

We can

- Develop a broader, shared understanding of frailty, which recognises that frailty may occur at younger ages

- Move beyond an "open door" approach to services, and reach out to underrepresented groups

How can we do this?

1. Service providers can ensure staff receive training on frailty with a needs-based rather than age-based approach, which includes information on the wider determinants of frailty

2. NHS providers can routinely assess for frailty in younger patients with multiple health conditions or conditions associated with high risk of frailty

3. Local commissioners can work with NHS providers to commission assertive outreach and community engagement to reach populations experiencing inequalities

Chapter 3. Why are people experiencing disadvantage and frailty not accessing health and care services and how can we improve access and experience?

We can

- Enable patients to play a key role in shaping services so that they are welcoming and inclusive for diverse communities

- Treat all patients with respect and ensure their rights to access health and care services are fulfilled

- Ensure that disadvantaged patients living with frailty are offered information that is accessible to support them to access care and support

- Offer advice to patients who may have practical difficulties getting to appointments

How can we do this?

1. Commissioners can refer to NHS England guidance on Diverse and Inclusive Participation, to involve diverse communities in the development of welcoming services

2. Primary Care Networks can take a broad approach when assessing local population health and risk, with a focus on groups experiencing poverty and Inclusion Health groups

3. CCGs, PCNs and GPs can work together to ensure patients are never wrongfully refused registration in primary care

4. Services can develop accessible information for people living with frailty about the meaning of frailty and how to manage the condition long-term

5. CCGs can commission accessible services by identifying communication preferences, providing accessible information, and providing access to interpretation services

6. Services can signpost and provide advice on travel to health and care appointments including transport options and costs

Chapter 4. How can we support people experiencing early frailty to manage their health and care?

We can

- Address multiple needs holistically to support patients to engage with care

- Develop support options for self-management of frailty that are inclusive and responsive to communities

How can we do this?

1. ICSs can establish better continuity by implementing good record sharing, such as single care records, with accessible information available

2. Primary care providers can offer extended consultations and holistic, patient-centred reviews for long-term conditions to people with multimorbidities

3. Local commissioners can work with NHS providers and the voluntary sector to develop co-located "one stop shops" for advice and clinical services

4. Local commissioners and services can develop inclusive and asset based education programmes on self-management in partnership with the voluntary sector

Introduction

"Frailty is where someone is less able to cope and recover from accidents, physical illness or other stressful events. It should be treated as a long term condition throughout adult life. This means starting with prevention and early identification of frailty and supporting people appropriately on the basis of their needs through to the end of their life"

NHS England and NHS Improvement[1]

Frailty is a health state characterised by a loss of in-built reserves and associated with vulnerability to adverse outcomes.[2] It is a condition involving low energy, slow walking speed and poor strength.[3] There is mounting evidence of high rates of premature frailty amongst people experiencing multiple exclusion but, as frailty is usually associated with older age, there is often a lack of recognition of the prevalence of this state in people who are younger. [4]

This resource explores how we can work together to reduce health inequalities for people living with frailty. With evidence gathered from a scoping exercise, a call for evidence, eight focus groups and a seminar event, we have identified the key challenges disadvantaged people living with frailty currently face in accessing meaningful intervention and support, and offer practical advice on how these challenges can be overcome.

As we enter the World Health Organisation's Decade of Healthy Ageing (2020-2030), there is need to consider how we can achieve a vision in which everyone in society has access to support to stay healthy throughout the life course. The Government's Consensus Statement on Healthy Ageing includes aims to narrow inequalities, and to support everyone to maintain resilience throughout their lives.[5] Our resource provides insight into how we can work towards this goal by taking decisive action to enable disadvantaged people living with frailty to manage the condition, and their health, long-term.

Currently, there are huge and widening inequalities in life expectancy across the country. For males living in the most deprived areas in England, life expectancy was 73.9 years in 2016-18, compared with 83.4 years in the least deprived; for females, these figures were 78.6 and 86.3 years respectively.[6] For women in the most deprived 10 percent of areas, life expectancy fell between 2010-12 and 2016-18.[7] Inequalities in life expectancy between groups experiencing deprivation and those who are not are caused by preventable and treatable diseases.[8] People from groups experiencing deprivation and exclusion spend a greater proportion of their life in poor health.[9] These years spent in ill health are not inevitable, and can be prevented or mitigated with the support of civic, service-level and community interventions.

The groups involved in this project experience lower life expectancies than the general population, and less years spent in good health. For example, Gypsy and Traveller communities are estimated to have life expectancies of between 10 and 25 years shorter than the general population whilst the average life expectancy for a homeless person is just 47. [10][11] Recent research has demonstrated that people experiencing homelessness living in a hostel, with an average age of 55.7 (aged between 38-74) had frailty levels equivalent to people in their late 80's. In addition, there were a wide range of unmet needs and high rates of older age syndromes including cognitive impairment, falls, mobility impairment and multimorbidity.[12]

It is important to note that, many of the groups involved in this project are often invisible in datasets and there is therefore a need for further research on premature frailty among these populations. Despite this, given the socioeconomic disadvantage and low life expectancies experienced across the target groups, many of these populations will also be at correlating high risk of frailty, and of living with frailty earlier in life.

Access to health and care services is currently inequitable, leading to an "inverse care law" which means that those with the greatest need often also have the greatest difficulty in accessing and receiving appropriate care and support.[13] In response to this, the Health and Social Care Act 2012 set out specific legal duties on health inequalities that require NHS England and Clinical Commissioning Groups (CCGs) to:

(a) reduce inequalities between patients with respect to their ability to access health services;

(b) reduce inequalities between patients with respect to the outcomes achieved for them by the provision of health services".[14]

In response to inconsistencies in the delivery of healthcare services to specific groups experiencing premature frailty DHSC, NHS England and NHS Improvement, and PHE funded the project 'Reducing Health Inequalities for People Living with Frailty". The aim of this project is to share how services have successfully overcome barriers to healthcare for people experiencing deprivation, people who are homeless, people experiencing problems with substance misuse, people with learning disabilities, LGB&T people, people with mental health needs, people from Gypsy and Traveller communities, and vulnerable migrants.

Methodology

In order to inform the findings and recommendations of this report we:

1

Carried out a scoping exercise incorporating 219 studies from over 30 countries[1]

2

Carried out eight focus groups with patients from disadvantaged groups experiencing disproportionate levels of frailty

3

Disseminated a call for evidence of best practice in addressing inequalities around frailty

4

Held a workshop to test the findings and recommendations of our research

[1]This consisted of research across two online databases (Cochrane and PubMed), as well as electronic and grey literature searching. This involved searches using core terms "frailty", "resilience" and "vulnerability" with combiner terms relating to five research areas; early onset frailty; frailty relating to the target groups; the social determinants of frailty; inconsistencies in care delivery; UK policy and practice.

Friends Families and Travellers

Chapter 1: Why are certain groups at high risk of developing frailty and what can we do to address this?

Key issues

- **People who experience chronic exclusion across the wider determinants of health are at higher risk of experiencing frailty, and living with frailty earlier in life**

- **The wider determinants of health and psycho-social factors influence health behaviours which in turn put disadvantaged groups at higher risk of early frailty**

- **A significant number of people from disadvantaged groups report feeling that a lack of support for non-clinical needs makes it difficult to recover when unwell**

- **Exclusion across the wider social determinants of health can impact social and community engagement and place people at risk of social isolation**

The conditions in which we work and live, known as the "social determinants of health", affect our health outcomes and life expectancy.[15] All of the groups included in this project experience exclusion or inequalities across the social determinants of health. For example, both pre and post migration circumstances mean that more than 61% of asylum seekers experience serious mental distress; low employment levels among people with learning disabilities contributes to poor mental and physical health; and the disproportionate location of Gypsy and Traveller sites by motorways and sewage works contributes to high rates of respiratory problems and long-term illness.[16][17]

"When you're a Traveller your body's actually older, because you've been out in the elements without heat, without comforts. A lot of people are diagnosed with arthritis and problems with bones and joints from the way of life that we live from being young…I was extremely fit, but now my body feels a lot older. My back is stiff; the cold is setting in; and I can feel that I have no strength in my hands. Stress is the main thing."

Participant in focus group by Friends, Families and Travellers

When we consider why certain groups are at high risk of frailty, the impact of these social and environmental factors is crucial. Our review of existing research and grey literature confirmed that factors such as low levels of education, issues with employment, and insecure housing leave people at significantly higher risk of experiencing frailty, and of living with frailty earlier in life.[18] This issue is likely to be compounded for people experiencing multiple disadvantage and exclusion across all of these areas. From our research, we found that greater opportunity in these areas improves a person's chances of healthy ageing. For instance, access to adequate housing and employment can be protective factors against frailty for those experiencing socioeconomic disadvantage.[19]

The development of frailty has serious health and resource implications for everyone, but people experiencing inequalities are at greater risk, both of developing frailty and developing frailty earlier. This has two important implications as we attempt to address inequalities around frailty. Firstly, to support early intervention, prevention and management of frailty, it is necessary to take a holistic approach to people's needs, which includes environmental factors. Secondly, if health and care services respond with a one size fits all model, this will be insufficient to tackle the gradient of health inequalities experienced by disadvantaged communities.
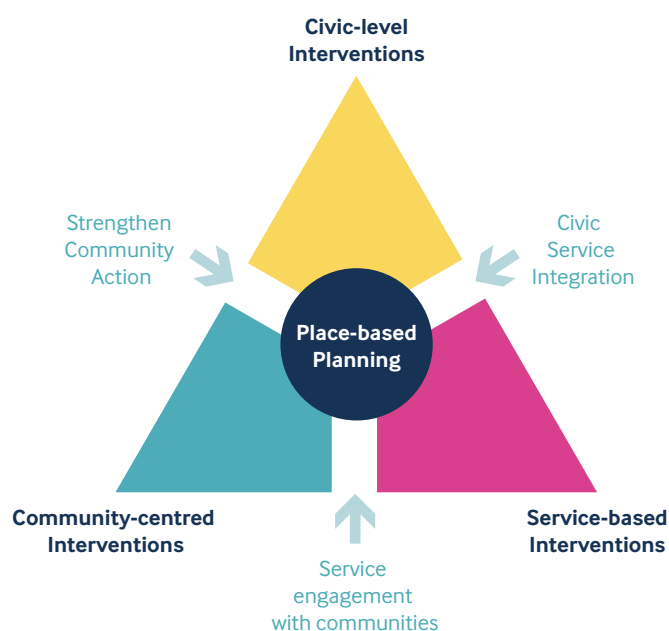
When discussing the factors that contribute to poor health, participants informing this report described numerous difficulties with housing, employment and income. It was felt that health encounters offered the opportunity for support and advice around broader needs, but that often these would be neglected to the detriment of long-term health and wellbeing. This was particularly emphasised by people who are homeless, insecurely housed or from Gypsy and Traveller communities. Participants discussed experiences of being discharged from hospital back to the street, and of evictions or seizures of vehicles that people lived in during periods of serious illness.

Participants also emphasised that these challenges contribute to social isolation. People from vulnerable migrant communities stated that being relocated for social housing makes it hard to be part of the local community, and results in a loss of valuable support from family, friends and peers. Participants who are homeless, experiencing substance misuse, or have a learning disability reported particularly high levels of isolation, with limited social networks and opportunity for support. Patients who identify as LGB&T also report very high levels of social isolation; in the 2019 GP Patient Survey, patients who identify as lesbian, gay or bisexual were most likely to report feeling isolated from others in the past 12 months.[20] The health impacts associated with loneliness are comparable to smoking, and people who are more socially isolated have lower fitness levels, more co-morbid illnesses and are more likely to be living with frailty. [21]

Positive solutions

In order to prevent premature frailty, we must work to improve the wider determinants of health faced by our target groups. To be effective, a collaborative place-based approach to tackling inequalities is needed, which capitalises on assets within the community and involves all of the actors that have the opportunity to influence and improve health outcomes. As outlined in PHE's Place Based Approach for Reducing Health Inequalities, this requires interventions across the civic, service and community sectors. [22] A joined-up approach can support primary, secondary, and tertiary prevention of frailty.

Population Intervention Triangle,
as in PHE's Place Based Approach for Reducing Health Inequalities

Civic-level Interventions

Strengthen Community Action

Civic Service Integration

Place-based Planning

Community-centred Interventions

Service engagement with communities

Service-based Interventions

As part of this approach, we need to tackle the gradient of health inequalities faced by disadvantaged groups. This can be supported by drawing upon Michael Marmot's concept of "proportionate universalism", which involves action that is universal, but proportionate to the level of need. [23] Within the context of frailty, we need to ensure that disadvantaged groups are always included within strategies to promote healthy ageing, and that the intensity of the response provided corresponds to the level of disadvantage.

To ensure that our target groups are reached by efforts to address frailty, there is need to move beyond an age-based approach to the condition. Current clinical practice is almost exclusively aimed at people over 65, but disadvantaged groups are more likely to experience typically age-related health problems such as frailty earlier in life. In recognition of this, the WHO's Global Strategy on Healthy Ageing focuses on "functional ability" rather than age.[24] By designing services around a needs-based rather than age-based approach, commissioners can ensure that disadvantaged populations have the opportunity to access secondary prevention for frailty, which halts progression of the condition to a more severe stage.

To address inequalities in frailty prevalence there is also need to establish primary prevention that promotes healthy ageing and forestalls the onset of the condition. To achieve this, we need to develop services that will help to influence and secure improvements across the wider determinants of health, whilst strengthening communities and social networks. The Social Value Act (2013) requires people who commission public services to think about how they can also secure wider social, economic and environmental benefits. [25] Whilst some of the areas targeted for social value contracting are beyond the realm of healthcare, this approach is a useful tool to help commissioners secure far-reaching benefits. Despite this, social value contracting remains underdeveloped within the NHS, and research in 2017 found that only 13% of CCGs were able to demonstrate active use of the Act.[26]

The NHS Long Term Plan incorporates aims to widen, diversify and make accessible the use of social prescribing across the country. If commissioned and implemented effectively, social prescribing could be a key vehicle to support reductions in health inequalities, and may support health services to meet Social Value Act requirements. [27] To date, social prescribing has primarily focused on targeted interventions for specific conditions and alternative interventions for mental health. Less emphasis has been placed on referrals that seek to address the wider determinants, such as advocacy and advice around housing, debt, income, employment, etc.

Expanding the use of these interventions can help to address the environmental factors that drive frailty, and strengthen social networks. [28]

"After Dad came out of hospital a lady came out to see him and told him he wasn't entitled to any benefits. He'd had a bladder operation, and bladder cancer, and had already had open heart surgery. It took our support worker from FFT a year to fight for that and to get him the benefits he needed".

Participant in focus group by Friends Families and Travellers

For people who are living with moderate or severe frailty earlier in life, engagement with community organisations can support tertiary prevention for frailty. Tertiary prevention aims to reduce the impact of an ongoing condition, by helping people to manage the condition long-term, and focussing on improving quality of life. Across all focus group discussions, charities and community groups were perceived as a key asset for aiding recovery when unwell and for accessing consistent support for a range of social needs.

"I was ok till my husband died and then I was lonely and worried about collapsing on my own, but now I go out almost daily thanks to the people here, we all go to the same clubs."

Participant in focus group by Trust for Developing Communities

"This [community centre] is the first place that helped me feel better. After I come here, it's an open door for me."

Participant in focus group by FaithAction

To support the implementation of community interventions, commissioners can refer to Nesta and the Health Foundation's Guidance on "Realising the Value". [29] This demonstrates the benefits of social prescribing, health coaching, education and peer support, and outlines how person and community-centred ways of working can be implemented within the health and care system. Whilst establishing this approach, NHS commissioners should ensure that community organisations are fully resourced to meet increased demand from social prescribing by making provisions towards community advocacy and advice services.

To ensure that approaches such as social prescribing are implemented to effectively address the needs of disadvantaged groups, it is important to acknowledge that many of these groups may face barriers to accessing primary care services, and greater difficulty sustaining engagement with community activities and programmes. To provide greater opportunity to offer relevant social prescribing to people living with frailty, community organisations and centres can also act as referrers for social prescribing, rather than simply recipients. Offering prescribing from places people are already visiting, such as community hubs and faith centres, can increase opportunity for engagement with relevant services. Whether offered in primary care or community settings, referrals should be focussed on responding to the greatest needs people have, such as advice or advocacy support around issues with debt, unemployment, or homelessness.

Strong links between primary care and community organisations is key to the success of social prescribing, and as part of this, the role of community pharmacy teams is crucial. Across the focus groups, pharmacies were seen to offer greater consistency of care than other health services. In particular, participants experiencing substance misuse expressed very high-levels of mistrust of the majority of services and low levels of social support from family and friends. Whilst opinion of specialist drug treatment services was low, pharmacies were valued and trusted. Community pharmacy therefore offers a key opportunity for signposting to people at particularly high risk of social isolation and poor health. Pharmacy settings can also provide the opportunity for people to engage with some screening, testing and brief interventions, which they may otherwise have difficulty accessing.

In order to maximise opportunities for signposting and early intervention for frailty, there is need for a shared commitment to addressing the needs of disadvantaged groups. Whilst some of the factors that drive inequalities are beyond the reach of healthcare services, integrated working across sectors can support to address patient needs more broadly. As NHS England establishes new collaborative ways of working across Integrated Care Systems, lessons from established approaches will be invaluable.

As highlighted in the case study below, spotlighting the work of Justlife and the Pathway team, addressing the needs of people who are homeless, insecurely housed, or living nomadically, requires strong links across NHS, community and civic services. Whilst the Homelessness Reduction Act (2017) imposes a duty for professionals to refer homeless people in hospitals to local authority housing teams, NHS services and local authorities can go beyond this by actively collaborating with charities.[30] Clear lines of communication across services, and multiagency working, can prevent patients from being discharged to the street, or having vehicles impounded at crucial points of ill health.

To ensure that collaborative working is successful, individual action from health and care professionals will have a key impact on engagement with underrepresented groups. With this in mind, intervention and support for management of frailty requires a person-centered care approach that considers the specific needs and priorities of the individual. This can be of particular importance for patients living with severe frailty who may require advanced care planning or end of life care. Enabling patients to play an active, engaged role in health care can improve patients' quality of care and health outcomes.[31]

As discussions with participants highlight, this approach will require efforts to build upon the key assets that help people to recover, including social networks and support. It is important to note that there may be cultural or identify-specific factors for professionals to consider in this context. For instance, older LGB&T adults are more than twice as likely to live alone, to be single or without children, and are much more likely to have a "chosen family" that they are not biologically or legally related to.[32] Ageing and illness can threaten these networks, and there is need for healthcare professionals to recognise the potentially crucial role of nonrelatives as a source of support in care planning and decision-making for these communities. [33]

During our focus groups, we heard a clear call for personalised health and care services, which are responsive to the complex realities of people's lives. Moving towards a personalised model of healthcare can support people to manage their physical and mental health and wellbeing, strengthen community resilience, and enable people to make proactive and informed decisions around their care.

As part of this approach, there is need for services to acknowledge the impact of stressors such as poverty, issues with employment, and insecure housing on engagement with care. Care providers can take simple steps to ensure these factors are considered. For example, services can take a compassionate approach to discharge procedures for patients who did not attend appointments. If patients are from particularly disadvantaged groups, known to have difficulties accessing mainstream services, care providers can seek to understand what support would help patients to attend, and aim to put this support in place, rather than automatically discharging patients. In addition, offering the opportunity for some drop-in appointments would benefit patients who may be experiencing chaotic lives as a result of multiple disadvantages across the wider determinants of health.

Four ways of reducing risk of frailty for people from disadvantaged groups:

1. Service providers can design services around a needs-based rather than age-based approach, using the World Health Organisation's definition of "functional ability".

2. Local commissioners can ensure that the range of support available to people through social prescribing meets the needs of populations at the greatest risk of poor health.

3. Local systems can invest in and work with charities, advocacy and advice services, and community groups to support with issues across the wider determinants of health.

4. Local commissioners can support community pharmacy to identify people at particularly high risk of social isolation and poor health and signpost to relevant services.

A spotlight on Justlife Health Engagement Workers: overcoming barriers and addressing social needs

Justlife's health engagement project is a responsive support service for homeless individuals in Brighton & Hove, funded by NHS Brighton CCG. Working closely with specialist homeless GP service Arch Healthcare, the local NHS Foundation Trust, and homeless healthcare charity Pathway, the team support homeless and insecurely housed clients to take ownership of their health concerns. For example, they provide support (including financial support) to ensure that clients attend medical appointments, they help to break down communication barriers by explaining medical jargon to clients, they support with substance dependency prescriptions, and they brief ward staff on patient needs. In addition, they ensure that the NHS Trusts' duty to refer to the local Housing Options team is fulfilled and that Adult Social Care carries out any necessary assessment under the Care Act. Between 2012 and 2019, Justlife supported 1700 people living in emergency or temporary accommodation, contributing to a 33% reduction in unplanned hospital admissions and a 47% reduction in the hospital re-admission rate.

Top tips from Justlife:

1. Advocates both support the people they work with to have their health needs met and support statutory services to fulfil legal duties owed to those in need

2. Ensure that the project is totally client-centred and agile to respond to client need

3. Collaboration with all relevant statutory and non-statutory agencies is fundamental to the successful delivery of the project

4. Providing financial assistance, in the form of bus passes and taxi fares, is vital as it can be prohibitively expensive to attend numerous appointments across the city

For more information, contact Martin Coll: martin@justlife.org.uk

Chapter 2: Why are current efforts at identifying frailty missing these groups and what can we do to address this?

Key issues

- **Lack of understanding of the term "frailty" means that many health and care professionals are unaware that this can affect people below the age of 65**

- **Missed opportunities for interventions to identify and manage frailty amongst people experiencing disadvantage means that issues may only be picked up at an urgent stage**

- **People from disadvantaged communities are less likely to access health and care services to begin with, and report low health aspirations**

- **Some groups reported that professionals may not identify when they are unwell, and symptoms can be missed**

Whilst policy and practice around frailty is rapidly developing, there is some ambiguity around the definition and use of the term. In 2015, Britain Thinks conducted a study on behalf of Age UK and the British Geriatric Society exploring language and perceptions of frailty. Their research found that both older adults and non-specialist healthcare professionals associated frailty with a significant decline in health or a need for end of life care.[34] Many patients and professionals therefore perceive frailty as a permanent state, rather than a condition that can be manageable, and potentially reversible. However, evidence demonstrates that providing complex holistic interventions to those diagnosed with frailty, such as the Comprehensive Geriatric Assessment, is effective in reducing mortality, reducing the risk of hospital admission, and improving independence.[35]

A small number of the participants in this project expressed a positive view of a diagnosis of frailty, and felt that this could help to access holistic support and intervention from services. However, one participant emphasised that conflicting perceptions of the condition among professionals, and a lack of shared understanding that frailty can affect younger people, creates obstacles to accessing consistent support:

"When the doctor put it down I thought 'ooh that sounds harsh'. But I felt it and I couldn't tell the lads, I couldn't tell anyone. However, it was very helpful and would have assisted if I had continued to apply for Universal Credit… I didn't get such good support from the next GP — the woman said: 'why has frailty been put down?' She was really horrible. It got me depressed and you are miles from the lifestyle you used to live."

Participant in focus group by Friends Families and Travellers

Although frailty at any age is associated with an increased risk of poor health and mortality, clinical practice almost exclusively targets people older than 65 years and there is little guidance available to professionals on when to assess for frailty in younger patients.[36] This contributes to missed opportunities to identify younger people living with the condition and to offer relevant intervention. As such, disadvantaged people living with early frailty are more likely to experience a deterioration in their health before their needs are addressed.

We heard from participants with learning disabilities that professionals sometimes assumed symptoms they were experiencing were due to their learning disability and did not offer assessment for frailty. This issue can contribute to poor health outcomes that may be preventable. A previous inquiry into premature deaths among people with learning disabilities found that 38% of people with a learning disability died from an avoidable cause, compared to 9% in a comparison population of people without a learning disability.[37] This diagnostic overshadowing can also similarly affect people with a mental health diagnosis, people experiencing substance misuse, and trans people.

When we consider why disadvantaged populations may be missed by efforts to identify frailty, it is important to note that these groups are often less likely to access health and care services to begin with. Disadvantaged groups experience more episodic and short-term involvement with services, and socioeconomic disadvantage is associated with greater attendance in A&E. [38] During focus group discussions, some participants were able to pinpoint specific points at which their health had deteriorated or where there had been opportunities for prevention.

"One more thing, one more thing and you start to go down that road. You worry about a fall and then you do become frail, and it is avoidable".

Participant from focus group by Friends, Families and Travellers

A key barrier to accessing care raised by participants was around low health aspirations. Participants felt that experiencing poor health at younger ages was simply a reality of their lives. Although many participants were experiencing poor health compared to the general population, participants emphasised that their health was good in comparison to their peers. This was particularly expressed by people who were experiencing homelessness or experiencing substance misuse, and it was reported that, unless health problems escalated in severity, most would be dealt with independently.

"We're doing OK because we're still alive, so many [people we know] aren't ......"

Participant from focus group by Collective Voice

When describing how tiredness and depression meant he missed health care appointments, one participant in the focus group by Homeless Link said his default position was to "suffer in silence".

"I only went and got [medical] help when it was get help or die"

Participant from focus group by Collective Voice

Positive solutions

To ensure that opportunities to offer meaningful intervention for frailty also reach disadvantaged patients experiencing frailty earlier in life, we need to develop a broader, shared understanding of the condition. Some commissioners provide health and care professionals with training on frailty and on key points at which to offer assessment. Broadening this training to encompass a needs-based rather than age-based approach would establish a greater understanding among care staff that frailty can occur earlier in life. To support this, incorporating guidance on the wider environmental factors that contribute to the early onset of frailty would help professionals to identify younger patients who may benefit from assessment.

With greater awareness of the key drivers of frailty among care staff, we can support services to maximise opportunities for assessment and intervention among disadvantaged populations. Identification of frailty may also assist patients to access support from social care services, and entitlements under the Care Act (2014), which they may otherwise have difficulty accessing.

Although not synonymous with frailty, multimorbidity is strongly correlated with the condition.[39] The NICE guidance on clinical assessment and management of multimorbidity advises that care professionals consider assessment for frailty in patients presenting with multiple health conditions.[40] This is particularly relevant for patients from disadvantaged populations, as multimorbidity is associated with socioeconomic inequalities, and people in deprived areas are known to develop multiple conditions 10-15 years earlier than people in more affluent areas. [41]

There is also evidence that younger patients with particular long-term conditions may be more likely to be living with frailty. Hanlon et al., found that the top five associated long-term conditions were multiple sclerosis, chronic fatigue syndrome, chronic obstructive pulmonary disease, connective tissue disease, and diabetes.[42] Care professionals can also consider assessment in younger patients diagnosed with key indicator conditions such as these to support early intervention.

Whilst maximising opportunities for assessment at point of contact with services will support in identifying disadvantaged people with early frailty, we also need to reach out to people who may not be accessing services. To support this, commissioners can move beyond an open door approach to service delivery. Developing assertive outreach services to reach communities who are underrepresented will enable health and care professionals and members of the voluntary sector to build trusting relationships with populations experiencing inequalities.

The reasons why individuals might not be accessing services are diverse. It may be because they are already experiencing so much stress in other areas of their life that adding health appointments may feel overwhelming, it may be because they don't realise services exist or welcome people like them, it may be because they have been turned away from services, or have had bad experiences in the past, or it may be that people's only experiences of health services may be in receiving bad news. By developing assertive outreach to underrepresented communities, NHS providers and the voluntary sector can build understanding of the issues experienced by individuals and put in place strategies to address these.

Assertive outreach is often most successful when delivered by or in partnership with people from the communities, and when outreach workers have time to build trusting relationships and help people with the issues they are most concerned by. Once trusting relationships are developed, it is easier to signpost, build confidence and link people into mainstream services.

Three ways of improving identification of early frailty among disadvantaged groups:

1. Service providers can ensure staff receive training on frailty with a needs-based rather than age-based approach, which includes information on the wider determinants of frailty

2. NHS providers can routinely assess for frailty in younger patients with multiple health conditions or conditions associated with high risk of frailty

3. Local commissioners can work with NHS providers to commission assertive outreach and community engagement to reach populations experiencing inequalities

A spotlight on the Boater Outreach Café at Julian House

The Boater Outreach Café provides support and signposting to the boating community, with the aim of improving access and engagement to services. The project is a collaboration between the Canal Ministries and the Gypsy, Traveller & Boater Support Service (funded by Virgin Care) The outreach model of the service is integral to its success in engaging with isolated and vulnerable boaters. The rural location of the Kennet and Avon canal makes it difficult for boaters to access services in towns; more so for people with mobility issues, and those experiencing frailty. By mooring in places where vulnerable boaters live along the canal, and offering a neutral space with free hot food and drinks, boaters can meet with other members of the boating community. This strengthens ties, builds resilience and helps to reduce isolation.

Top Tips from Julian House:

1. Community response and engagement is the best way to achieve lasting and positive change

2. New approaches and learning are essential to respond effectively in an environment where pressures have grown, and resources have diminished

3. Providing a welcoming, neutral space for people to engage with workers gives boaters comfort and safety in asking for help, and allows them to access knowledge, expertise, and signposting to other organisations

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Chapter 3: Why are people experiencing disadvantage and frailty not accessing health and care services and how can we improve access and experience?

Key issues

- **Participants described being turned away from health and care services, feeling stigmatised, or not being taken seriously, leading to low expectations and a lack of trust in services**

- **Participants stated that issues around communication, including a lack of accessible information or access to interpreting services, made it difficult to engage with care**

- **Many of the project participants reported practical difficulties in accessing services, including lack of transport and long travel times to services**

The Health and Social Care Act is clear that all service users must be treated with dignity and respect, having due regard to any relevant protected characteristics.[43] Despite this, many participants described feeling judged, stigmatised and discriminated against when accessing health and care services. Some people stated that they had been turned away from services as a result of perceived discriminatory attitudes from professionals, and a number of participants with no fixed address had been denied registration at GP surgeries despite there being no regulatory requirement to prove identity or address.

Research released by Friends, Families and Travellers in March 2019 found that 24 out of 50 GP practices contacted in England would not register a mystery shopper from the Traveller community who had no fixed address and no proof of identification.[44] Advocacy organisation Doctors of the World found that in almost one fifth of over 2000 attempts, GP practices refused to register migrants in vulnerable circumstances.[45] The same issues affects people experiencing homelessness and those in contact with the criminal justice system.

In many cases, disadvantaged groups are excluded or discouraged from GP practices due to unnecessary logistical barriers, rather than a direct refusal to register. A number of participants reported that issues around communication exacerbated the difficulties they faced in accessing and using services. Within FFT's focus group it was noted that many people from Gypsy and Traveller communities have low or no literacy (45% of FFT's beneficiaries) and are therefore excluded from health messages or information about care. Some people reported difficulty completing GP registration forms and a lack of support with this from professionals. This issue also affects people experiencing homelessness; a 2014 study found that around 51% of adults surveyed had poor literacy skills.[46] In focus group discussions with vulnerable migrants, participants also reported limited access to translation, which greatly impacted their capacity and confidence to engage with care and support.

Quotes from participants on discrimination

"GP surgeries for homeless people are better. When you go in there and say you have no fixed address they don't look down on you. They're not asking you the silly questions that you get embarrassed by in front of the whole surgery."

Participant from focus group by Friends, Families and Travellers

"I don't like to keep coming out to doctors, it stops me talking."

Participant from focus group by Mesmac

"I do not feel I was being treated like a person, just a diagnosis."

Participant from focus group by AMHP

"Everyone hates us and we know it."

Participant from focus group by Collective Voice

"I feel I've been through hell and mistreated just because of the way I look and because I looked a bit grubby and have dirt up my nails. The damage the lack of care has done to me means that the rest of my life is ruined"

Participant from focus group by Friends, Families and Travellers

"My mum asked the hospital to explain things to me. I wouldn't have a clue if they used jargon."

Participant from focus group by CHANGE

Quotes from participants on communication

"I wish they would tell me which illness I have, maybe it's [a] chronic illness, but I don't know."

Participant from focus group by FaithAction

"Before I could speak English I stayed home, I was scared. They [GP] didn't know what we say. But now I'm OK. I can go speak with the GP on my own. Because sometimes your husband [is] not with you … Now I'm not good at English, but I manage."

Participant from focus group by FaithAction

"The hospital staff talked to my family, not to me."

Participant from focus group by CHANGE

Participants with learning disabilities emphasised that failure to provide accessible information results in patients experiencing a lack of clarity about their care and subsequent anxiety around their health. It was stated that this issue is exacerbated by a perceived lack of understanding among some professionals on how to communicate with patients who have learning disabilities. Participants reported that professionals often speak to carers or family members instead of the patient, and that this prevents people with learning disabilities from taking an active role in their health and care.

In addition to these challenges, many participants stated that physical barriers prevented them from being able to get their foot in the door of services. Some participants were experiencing financial difficulties, and had limited mobility, which resulted in difficulty accessing transport or travelling to appointments.

"I cannot see the number of the bus. If people are there I can ask, but sometimes there is nobody there."

Participant from focus group by FaithAction

"We will have a situation wherein patients are being charged because they will not be able to get to their appointments, which is terrible."

Participant from focus group by FaithAction

Positive solutions

To support disadvantaged people living with frailty to access services, it is imperative that services are intentionally inclusive and committed to tackling all forms of stigmatisation and discrimination. The Equality Act 2010 makes clear that it is unlawful to discriminate against someone because they belong to a protected characteristic group.[47] It is important for services to recognise that discrimination can occur indirectly due to logistical barriers, as well as due to direct stigmatisation. Whilst some participants in this project are members of protected characteristic groups covered by the Equality Act, others are not. In order to support underrepresented communities to access services there is need to go beyond legal duties and to develop services that are welcoming and inclusive to all.

To support this, we need to ensure that patient voices play a key role in shaping healthcare services. Commissioners can support this by referring to NHS England guidance such as 'Diverse and Inclusive Participation', and 'Patient and Public Participation'.[48] NHS England highlights that effective participation enables services to benefit from diverse perspectives that can improve the quality of decisions.[49] These guides include recommendations to connect with charities to develop relationships with diverse communities, and ensure that health care professionals are trained in cultural awareness, inclusion, equality and diversity.

In order to build compassion and understanding of the experiences of disadvantaged populations amongst health and social care professionals, services can invest in training. Incorporating people with lived experience of exclusion in the production of training and education for professionals enables services to tap into insights about key challenges to accessing good quality health and care that may otherwise go unidentified or unaddressed.[50] Offering the opportunity for healthcare professionals to engage with the experiences of specific communities can also provide relevant insight into cultural attitudes and values that influence patient engagement with services.

To support services to reach underrepresented groups there is need for healthcare professionals to understand the needs of the local population. The NHS Long Term Plan incorporates commitments towards greater action on health inequalities and prevention, and by 2021, Primary Care Networks (PCNs) will assess local population risk and provide targeted support to those patients who need it most.[51]

To encompass the needs of the most underrepresented groups, particular attention should be given to groups who are at the sharp edge of inequality and known to face significant social exclusion and some of the poorest health outcomes in England. [52] This may include Gypsy and Traveller communities, vulnerable migrants, sex workers, homeless people and more. In the absence of NHS data collection on some groups experiencing sharp health inequalities, PCNs will need to identify non-health datasets, such as employment, education, housing, etc. to ascertain local population size of specific groups and engage with members of these groups to understand the nature of unmet need.

To build on this, we can take steps to ensure that all staff at GP surgeries understand their responsibility to register patients with no fixed address, no identification, or no proof of immigration status. In order to build a picture of local issues around registration, Clinical Commissioning Groups can ask local voluntary sector organisations, including Healthwatch, to carry out mystery shopping exercises at GPs and dentists. In response to local need, training can be provided to support in addressing issues with access to general practice. Pathway and the Faculty for Homeless and Inclusion Health have developed a training package for GP receptionists to support services to meet this requirement.[53]

In addition, it is important that primary care services moving towards increasingly digitised approaches to registration and appointments, do not make their processes "digital-by-default". Groups facing inequalities and disadvantage are more likely to be experiencing digital exclusion as a result of low literacy, low levels of English, and practical barriers such as lack of access to data or devices. Services can ensure that digital exclusion is not a barrier to care by offering alternative options for registration and access. Telephone consultations and support to complete registration forms over the phone can ensure that disadvantaged groups do not face increased difficulty accessing primary care appointments.

To support disadvantaged people living with frailty to access health and care services and ensure consistent quality of care along the care pathway, we can address communication barriers. The Accessible Information Standard (AIS) states that people in England have the right to accessible information and communication support and provides guidance on how to achieve this.[54] Whilst the Standard is specifically targeted at patients, service users, carers and parents with a disability, impairment or sensory loss, many of the principles apply to communicating with people with low literacy or low levels of English.

As previously noted, in order to support disadvantaged communities living with frailty to access care and support, we need to develop a common understanding of the condition among professionals and patients alike. To do this, we can ensure that communities with low levels of literacy and people with learning disabilities are not excluded from information about the meaning of frailty, how to manage the condition long-term, and relevant support options available. The commissioning of accessible information on the condition for people living with frailty would ensure that disadvantaged populations are also able to benefit from the increasing advice and guidance available to the general population.

16.4% of adults in England can be described as having "very poor literacy skills", and services that improve communication with people with low literacy can therefore improve accessibility for a significant section of their patient group.[55] To achieve this, services can use patient management systems to identify and flag patients who need extra support. This would enable services to offer double appointments for people with low literacy, and prompt staff to offer support with form filling or to provide verbal explanations for paperwork. Services can also invest in technology that aids communication with people with low literacy – using voice recordings, videos, or easy read English in all communications.

In addition, commissioners can refer to NHS guidance on Interpreting and Translation Services in Primary care to ensure that vulnerable migrants with low levels of English are supported to access services.[56] When providing interpreting, professionals can consider that some groups, such as Roma communities, experience discrimination within their origin countries. Within smaller communities, patients may also know the interpreter for their language, and may not be comfortable for this person to provide translation. To address this, commissioners can utilise access to cost-effective methods of providing interpreting, such as telephone interpreting or app-based support.[57]

Many of the groups involved in this project reported financial difficulties and difficulties accessing benefits, which mean they are unable to access private transport. People living nomadically or on Traveller sites may also be more likely to live in locations that are out of the way, with limited access to public transport services. In order to address this issue, care providers can link in with community organisations and volunteer driver schemes and offer information about alternative options where patients are not entitled to patient transport. In particular, if appointments are out of area or require long-distance travel, care providers should ensure that advice on travel options and costs is automatically offered.

Six ways of improving access to and experience of services for people experiencing early frailty from disadvantaged groups:

1. **Commissioners can refer to NHS England guidance on Diverse and Inclusive Participation, to involve diverse communities in the development of welcoming services**

2. **Primary Care Networks can take a progressive approach when assessing local population health and risk, with a focus on groups experiencing poverty and multiple disadvantage**

3. **CCGs, PCNs and GPs can work together to ensure patients are never wrongfully refused registration in primary care**

4. **Services can develop accessible information for people living with frailty about the meaning of frailty and how to manage the condition long-term**

5. **CCGs can commission accessible services by identifying communication preferences, providing accessible information, and providing access to interpretation services**

6. **Services can signpost and provide advice on travel to health and care appointments including transport options and costs**

A spotlight on Doctors of the World "Safe Surgeries" initiative

The Doctors of the World Safe Surgery initiative encourages all GP surgeries to commit to tackling the barriers faced by many migrants in accessing healthcare. At the minimum, this means that GP practices that sign up to become "Safe Surgeries" work to overcome barriers to primary care by ensuring that patients are not refused registration due to lack of ID or proof of address, or immigration status, and that low levels of English language is not a barrier to care.

Safe Surgeries help to tackle inequalities by ensuring that vulnerable migrant patients experiencing high levels of social exclusion are provided with accessible, welcoming and inclusive primary healthcare. To support practices to become Safe Surgeries, Doctors of the World provides a user-friendly toolkit, simple guides to NHS entitlement and translated patient-facing posters. They also facilitate networking events, and best practice training for clinical and non-clinical staff. [58]

Top tips from Doctors of the World:

1. Do not insist on documentation to access primary care

2. Ensure that this is communicated to all new and existing staff

3. Visibly demonstrate your commitment to access for all patients by displaying this in your surgery

4. Ensure that your registration procedures are not "digital by default" for those experiencing digital exclusion

For more information, contact info@doctorsoftheworld.org.uk

A spotlight on FaithAction's Creative English Programme

Creative English was developed by FaithAction and is based on Dr Anne Smith's PhD thesis that drama can facilitate belonging for refugee and migrant communities. The programme is volunteer-led and involves "soap opera" drama-based sessions, games and activities, to support people to learn and practice English within a relaxed and friendly atmosphere. The sessions are based around real-life scenarios, and follow the daily lives of different families living on the same street. Participants take on these roles and act out everyday situations, such as visiting the doctor. This supports people of different aptitudes, and those with low or no levels of English, to develop the confidence to communicate in every day settings.

The programme initially received funding from the Ministry of Housing, Communities, and Local Government (MHCLG) in 2013 to deliver Creative English through 36 "hubs" across the country as part of a £6 million scheme to reduce isolation and marginalisation of communities across England. There are now around 70 hubs delivering Creative English across the UK. Over 10,000 learners have benefited from Creative English classes to date, and 100% of those who had completed at least 10 sessions of the course said their confidence had improved as a result. Creative English was one of five programmes shortlisted for the British Council ELTons Awards 2015 for Excellence in Course Innovation, and FaithAction now offer the Creative English license, which gives organisations the opportunity to deliver the Creative English course themselves, supported by resources, guidance and training.

Top tips from FaithAction:

1. Rehearsing for real life scenarios in fun and creative ways can build people's confidence to engage with services

2. Moving away from more traditional formal approaches and offering flexible sessions, can help people who may have chaotic lives to access support

3. Focus on building confidence, not simply technical aptitude, to overcome language barriers

For more information contact info@faithaction.net

Chapter 4: How can we support people experiencing premature frailty to manage their health and care?

Key issues

- **Service delivery models oriented around single conditions can result in complex care schedules for people with multimorbidity and multiple health and care needs**

- **Participants report that they may have to re-explain their story to multiple professionals and that their needs can fall through gaps between services due to a lack of clear accountability**

- **People experiencing multimorbidity report that limited time with GPs means they have to prioritise between issues, and are left unsure of how to manage conditions long-term**

- **Services can be reactive to need, rather than proactive, resulting in limited opportunity for prevention and future planning among disadvantaged groups**

Although frailty can occur in the absence of other long-term conditions, people with two or more conditions are more likely to be living with frailty.[59] The majority of participants in this project had diagnoses of more than one long-term condition and, of those participants, many had been diagnosed with four or more conditions.

Participants emphasised that they wanted support to manage a number of conditions simultaneously, but that service delivery models are designed around single conditions, which results in complex and time-consuming care schedules. This was particularly seen as an issue for people with comorbid mental and physical health needs.

"I was frustrated that I was diagnosed with another illness...I had to have a lot of appointments but support wasn't really provided to treat all three conditions or take them all into consideration...I wasn't sure where to go next as the two physical conditions were impacting my mental health".

Participant from focus group by AMHP

"I felt like I had no control over anything, and I had to make so many changes to my life. My mental health was poor and now I had three other conditions to constantly worry about too"

Participant from focus group by AMHP

A number of participants emphasised that communication between professionals working with the same individual could be poor. It was felt that people could disengage from services as a result of a lack of clarity as to the responsibilities of different care providers, and frustration at the need to re-explain medical histories. Many participants described being "bounced around" from specialist to specialist, without clear accountability across services. One participant in the focus group held by the Association of Mental Health Providers stated that it had taken three years from the time they noticed there was a problem to eventually being given a diagnosis because "...nobody took responsibility".

Participants wanted guidance from GPs on how to manage multiple health problems, but frustration was expressed at what was perceived as a "one

appointment, one problem" issue in general practice. Many people felt that they had to prioritise one symptom or health condition over another, as they would be unable to articulate all of their needs in a 10 minute appointment. As a result, some medical needs or concerns were neglected, and it was felt that this could ultimately lead to a significant deterioration in health.

"One person is one person. Symptoms is not other people symptoms. It's all one person."

Participant from focus group by FaithAction

"I wasn't surprised...I thought the heart attack was well overdue because I had so many health problems."

Participant from focus group by Friends, Families and Travellers

As a result of limited time with GPs, it was felt across focus groups that future planning for long-term conditions was often not adequately communicated, which leaves patients unsure of how to manage their health and care needs.

"I was just left up to my own devices, really. I wasn't having any in-depth conversations with the doctor, he didn't have the time, it was just 'here's your tablets', you know?"

Participant from focus group by Homeless Link

"Sometimes you feel like doctors are just prescribing things to try and get rid of you. They don't always have the time to tell you what's going on, and they give you antibiotics instead"

Participant from focus group by Friends, Families and Travellers

Positive solutions

To enable people experiencing early frailty to better manage their physical and mental health, we need to adopt a holistic approach to care for patients who are experiencing multiple health problems, and reduce the complexity of care schedules. To prevent patients from having to re-explain medical histories, commissioners can establish better continuity across services by implementing good record

sharing systems. For example, the Integrated Care System (ICS) for Dorset has developed a single care record for each of Dorset's 800,000 residents. As a result, patients are no longer required to repeat their story to different agencies, and their wider needs are better understood across services.[60]

Due to historic mistrust of statutory services, some patients have concerns about information sharing; many people from Gypsy and Traveller communities are fearful of unfair treatment from social services involvement, some vulnerable migrants are fearful of information sharing with immigration teams or the Home Office, people experiencing substance misuse may be fearful that information will be shared with the police, and trans people may be fearful of their trans status or history being shared or revealed. As such, commissioners should offer accessible information on how single care records can benefit patients and where information will be shared. Dorset ICS has taken this approach with the provision of an easy read guide and video resource.

Many people with multiple conditions are currently invited to multiple annual care reviews by GP surgeries for separate conditions. In response to this, the "3D Study" trialed an intervention for patients on several Quality and Outcomes Framework (QOF) registers in which single condition reviews were replaced with patient-centred reviews with a focus on quality of life, mental health and polypharmacy.[61] Offering patient-centred reviews can improve experiences of care; participants in the study reported that their care felt more joined up and aligned to their priorities, and they understood better how to manage their health.

GP surgeries can also offer extended consultations to people with multimorbidity. This would offer the opportunity to address multiple health needs holistically and to enable better future planning. By equipping patients with the information and support needed to self-manage conditions, this can reduce the likelihood that health problems will escalate to an acute stage, and should minimise the subsequent demand placed on GP and secondary care services.

Patients experiencing disadvantage may have difficulty engaging with multiple services as a result of stressors from poverty, and issues around accommodation and benefits. Commissioners can address this by creating one-stop-shops in health settings. Co-location of services can increase access to advice interventions, podiatry, dental care and smoking cessation and more.[62] This can increase levels of engagement with health and care services and enable patients to manage their health and care more easily.

In addition to co-location of services, care providers can maximise opportunities for relevant interventions by proactively engaging with the needs of patients facing multiple disadvantage, and offering opportunities for future planning. As many disadvantaged groups experience fragmented engagement with services, and often once needs have reached an acute stage, opportunities for advanced care planning or preventative interventions may be less common. As such, care providers can aim to proactively engage with the needs of patients from socioeconomically disadvantaged groups by offering the opportunity for discussions around priorities and choices when patients do engage with care. Continuity of this care can be supported by ensuring comprehensive records are provided for patients who are likely to have transient engagement with services as a result of no fixed address or nomadic lifestyles.

In order to support people experiencing premature frailty to manage their health and care, healthcare services can invest in "patient activation". This refers to an individual's level of knowledge, skills, and confidence in managing their health and care. Patients with low activation levels are demonstrated to be more likely to attend A&E, to be hospitalised, and to be readmitted following discharge.[63] NHS England and NHS Improvement highlight that "patient activation is of particular importance to the 15 million people living with long-term conditions who rely, more than most, on NHS services".[64]

In order to support disadvantaged people living with frailty to better manage their health, commissioners can implement targeted "patient activation" options, such as education programmes, peer support and coaching.[65] It is important to note that a one-size fits all approach will not be sufficient to address the needs of disadvantaged groups who may have previously faced particularly negative classroom experiences, and received lower levels of education. Moving away from "top-down" service design, and instead working with charities and community groups with strong links to communities, would ensure that these services, and relevant health messages, are appropriately tailored to the populations they serve.

Four ways to support people experiencing early frailty to manage their health and care:

1. **ICSs can establish better continuity of care by implementing good record sharing, such as single care records, with accessible information available**

2. **Primary care providers can offer extended consultations and holistic, patient-centred reviews for long-term conditions to people with multimorbidities**

3. **Local commissioners can work with NHS providers and the voluntary sector to develop co-located "one stop shops" for advice and clinical services**

4. **Local commissioners and services can develop inclusive and asset based education programmes on self-management in partnership with the voluntary sector**

A Spotlight on General Practice at the Deep End: Yorkshire and Humber

General Practice at the Deep End: Yorkshire and Humber is a collective of general practices working on behalf the most deprived members of society. The network was inspired by the Deep End model, originally founded in Scotland by Professor Graham Watt, and there are now Deep End practices across the UK and internationally.[66] The aim of the initiative is to overcome the inverse care law in primary care; that those with the greatest health and care needs also have the greatest difficulty accessing services. Deep End GPs work to support patients in blanket, pocket or hidden areas of deprivation, and aim to share learning and best practice to support in reducing inequalities in access to primary healthcare and health outcomes.

GPs in deprived areas often work with patients with multimorbidity, and non-medical health issues around employment, housing, and social isolation. The Deep End model involves action to improve access to and experience of care, using methods such as extended consultations for people with multimorbidity complex care needs, embedding advice workers in general practice, and social prescribing.[67] The project has been funded by Health Education England (HEE) Yorkshire and Humber.

Top tips from Deep End Yorkshire and Humber:

1. Fund intersectoral meetings so that learning on best practice can be shared.

2. Support the development of expert and professional social prescribing.

3. Fund General Practice to provide flexible, person centred services.

4. Allow primary care professionals time to visit other centres of excellence to share best practice.

For more information contact e.walton@sheffield.ac.uk

A spotlight on Friends Families and Travellers (FFT) Patient Activation Project

Gypsy and Traveller Health Champions Project

FFT is an accredited Royal Society for Public Health (RSPH) Training Centre. The project is based on an asset-based peer-support model of health improvement. Participants are trained as 'Health Champions', which involves education on relevant health improvement messages, and the development of tools to enable them to share these messages with family members and peers. This supports individuals and communities to increase their own knowledge, skills, confidence and self-efficacy. On completion of the training, community members attain an accredited qualification, which is equivalent to a GCSE qualification, and supports access to education or career progression.

At FFT, 45% of service users have low or no literacy, which can be a huge barrier to accessing information or advice on health. The training has been developed to be accessible for people with low or no literacy. Over 70 Gypsy and Traveller community members have taken part in the training to date and for many participants, this is their first formal qualification. The project currently takes place in East Sussex and West Sussex and is in the process of being rolled out in Leeds and Hertfordshire. As a result of FFT's success in this area, this programme reached the finals for the Community Health Development Award as part of the RSPH Health & Wellbeing Awards 2019.

Top tips from FFT:

1. Establishing trust with communities is key to the success of the model

2. Achieving a qualification provides affirmation to people and improves their confidence in engaging with health and care

3. You have to meet people where they are at — don't come with an agenda!

For more information, contact Michelle Gavin, Projects Manager: michelle@gypsy-traveller.org

Conclusion

Our research demonstrates that inequalities and exclusion across the wider determinants of health means that people from disadvantaged groups are more likely to be living with frailty, and to develop frailty prematurely. In this report, we have demonstrated that a needs-based approach to frailty, which takes steps to address environmental factors, can ensure that disadvantaged groups are able to benefit from efforts to identify and manage the condition.

During our discussions with participants, we heard a clear call for services to reach out and meet people where they are, both literally and metaphorically. People expressed a positive view of services that were tailored to their needs and provided opportunities for support and engagement in familiar, community settings. We found a number of impressive examples of NHS Providers and voluntary sector organisations who are working in innovative ways to reach out to underrepresented communities, and to rebuild trust with patients who are disenfranchised by the health and care system.

Participants living with frailty provided insight into the challenges they have experienced in accessing and using health and services, including complex care schedules, communication issues, and experiences of stigmatisation and discrimination. We have outlined some practical steps that can support services to overcome these challenges, and to engage with patient needs in a holistic, person and community-centred way. Taking these steps can ensure that disadvantaged communities have the opportunity to access support to build their skills, knowledge and confidence to manage frailty long-term.

Sharing learning from inspiring examples of best practice, this guide offers simple, practical principles any health professional, service or local system can act upon to make a real difference in the lives of populations experiencing health inequalities and frailty.

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Contact us

Friends Families and Travellers is a leading national charity that works on behalf of all Gypsies, Travellers and Roma regardless of ethnicity, culture or background.

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