I'm still me.

...a narrative for coordinated support for older people.
Preface

We all like categories. They help us make sense of the world and feel more comfortable. And so we have 'young people'; 'middle aged people' and 'older people'. These familiar categories automatically entreat us to consider differences. Yet an extra moment's thought might redirect us to a view that any differences are actually smaller than the similarities of shared humanity between the groups.

An older person is not an alien species – simply our former selves grown older. Older people value today what they valued yesterday – that is, independence; life roles; connections with family friends and communities; fun; challenges; etc. etc. What needs to be recognised is not the 'oldness' of a person but their individuality.

It is this individuality that can so easily become submerged and hidden from view in the pressure caldron that characterises our contemporary health and social care system.

This older people's narrative serves to remind us of vital core values to which we all might lay claim – but restated through the eyes of an older person. In a sense it is a shame that there is a need to restate these values. But we are where we are.

Professionals and service providers need explicitly to reconnect with these core statements. The narrative is designed to lift the individual within the older person label into clearer focus – not an alien being but simply a human being who has lived longer.

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Core groups were created to steer the project, including:

- C partners, National Voices, London, and Cartners
- The British Geriatrics Society, the Elderly's Society, the British Geriatric Society, and older people's organisations.

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Introduction

The set of narrative statements published in this document describes the way older people want high quality coordinated care to support them. This document is intended to be used as an extension to the Narrative for person centred coordinated care statements published by National Voices and Thin Coalitions, to design care and support that is successful in achieving the outcomes that older people want.

Hy older people hy now urulation is ageing y e hours a day. The number of older people of the age is set to double in the next years and 3 is a consequence older populations are for a growing proportion of our society. The number of year olds has more than one long-term condition, rising to of year old. The majority of older people therefore have multiple physical and mental health needs which require them to or cross any care, secondary care settings and social care.

For older people living with frailty or co needs, health and quality of life is vulnerable to sudden changes ‘trigger events’ such as a fall, or a change in circumstances like the loss of a carer, can result in a rapid deterioration in health and significant loss of independence. It may also lead to sharp increases in the costs of care ith etter care planning and more tailored support, so any such episodes could be avoided, or the need could be at least anticipated and better managed.

Therefore, it is echoing a priority for health and social care systems to look at how they respond to the needs of older people. In particular, how they identify what those needs are in ris of such crises and how they then ensure that reactive strategies are in place. This enables services to inter one early and support older people to avoid distressing emergencies, which typically carry with them substantial human and financial costs.

Hy additional statements were needed. The Narrative for person centred coordinated care has identified a single, core on cross system definition of the goals for care integration. It was consciously designed to be ‘generic’ and equally relevant to all groups of older people who need to use multiple health and care services. This generic approach, however, might exclude some factors in the care of older people that are very significant to them, but not always relevant to other groups of people, including older people these services, set out to improve the health of older people living with frailty or co needs, health and quality of life is vulnerable to sudden deterioration in their health, possibly including crisis or hospital admission. They might be described by professionals as ‘frail’, but, as we discuss later, this is a term that older people themselves do not use.

Similar issues of other groups of service users—such as older people living with dental care—resulted in quite extensive sets of statements giving their articulation. There is a different need for the various services, and others are concerned about the outcomes that matter in relation to their lives.

This new Narrative sees to articulate these outcomes, and urges commissioners and providers to consider adopting these statements alongside the generic Narrative as the goals of care for older people, particularly those with co needs.
“I can go to bed when I want, get up when I want. I can think for myself. I don’t rely on other people, as long as I’ve got my mobility.”

1 National Voices & Think Local Act Personal (2013) A Narrative for Person-Centred Coordinated Care. 
4 erer (2011) The cottish chool of Pri ar Care's iti or idit esearch Pro ra e htt slideserve
5 National Voices & Think Local Act Personal (201) No Ass tions A Narrative for Personalised coordinated care and s ort in ental ealth. 
The 1 statements

Community interactions
- can maintain social contact as much as possible

Care and support
- can build relationships with others
- can plan care with others and carer(s) allowing control and input into the services to achieve the outcomes important to the
- Taken to other care and support to live the life at the end of a lifetime

Decision making
- can make own decisions with advice and support from friends and professionals if wanted

Independence
- a recognised for what can be done rather than assumptions being about what cannot
- as sorted to be independent
- can do activities that are important to the
- here are recognised as key to independence and quality of life
In order to develop a specific narrative for older people, reflecting the different perspectives and references of that population group, we needed to invest a lot of time listening to them, asking the ‘what matters most to you’ and reflecting on the experiences that emerged.

The research, carried out during a year and a half, included:

- A literature review of existing research and materials to understand the issues and provide a foundation for interviews to build on published and grey literature as included that contained the search terms older adults, frailty, frail, vulnerable, and person-centred, outcomes, care needs.

- An online survey and focus groups to gather the users of health professionals, care leaders, carers and older individuals, reflecting on the existing Narrative for Coordinated Care and suggesting additional elements that are relevant for older people associated in the focus groups and responded to the online survey.

- Ethnographic research conducted by ISS on behalf of ge to explore the experiences of living with frailty. The researchers spent around hours in homes, seeing the act of living with frailty and some of the ways older adults adapted to living with changing needs.

- 1:1 interviews with older adults exploring the things that are most important in their lives; their experiences of accessing services and support; and attitudes to terminology such as ‘frail’, ‘old’, ‘elderly’, ‘older’.

Interview research cohort:

- Average age of
- Ethnicity of participants fell in line with figures for London and England as a whole: British, Indian, Black, and others.
- Lived alone including in sheltered housing, lived with family, lived with a partner, and had other arrangements
- Owned their accommodation, rented, other
- Lived independently in their own homes
- Had formal support agencies in place, had no formal support
- Had formal support for all or informal support for some

P (201) understanding the lives of older people living with frailty A qualitative investigation P for A e htt a e k or k frailt
What matters most to older people: key themes

Independence:
Independence as described by the authority of the older people to do as one of the most important things to the For most this entails having a 'do hat I ant, hen I ant' and 'getting out and a out’

Support from either family and friends or formal carers to maintain a level of independence, particularly when ability as limited, as not seen to either ed independence In the interie and ethnogra hic or, eer ho ere su orted and a le to ada t to changing health needs ere a le to en oy a etter uality of life

Their erctions of their own health and erctions of their inde  endence did not necessarily correlate, suggesting that older e e do not ant to e de ned or liited y their diagnoses

There can e a tension et een

inde  endence and safety while several studies in the literature re e a out inde  endence and safety, they did not del e into the eaning of these and any studies a eared to e ery' ro le focused' rather than loo ing at the eer lih frailty the sel es as indiuals

Being a le to do acti ies that ere iortant to the , also hel ed to aintain a sense of achie e ent and identity For e a le, any interie ees descri  ed great ride in doing the ashing u or house or and disa oint ent hen these ha tu al tas s e ta en or y carers The or sho artici ants suggested that inde  endence as a out ore than attending to theasic acti ies of daily li ing ut a out eing a le to do acti ies hich ere eaningful to the and en ha ing the o portunity to try ne acti ies

Community interactions:
any of the older e e e e to said that they did feel art of their co unity But there as also a sense of e e anting to ha e control o er the a ount of social contact they had – so e anted uch ore social contact ut others alued ti e alone

any descri ed feelings of loneliness any said that they issed friends ho had died and in some instances, there as resignation that they could no longer e ect to ha e eer relat ionshi s This as often associated ith losing a artner

Sur risingly, in the interie cohort there as a higher correlation of self reported loneliness in those that li ed ith fa ili y than those ho li ed alone and therefore felt they needed to e e the effort for social interaction This highlights that ha ing fre uent social contact is not enough to re ent feelings of loneliness

Decision making:
Indiuals anted to retain choice and control of decision a ing Ho er any also descri ed the desire for clear guidance and su ort fro rofessionals and fa ili y In any instances fa ili e the rst ort of call for oth accessing su ort and for discussing decisions
“I feel lonely when I get up in the morning. I hate mornings...you want to talk to somebody about something, or you thought of something in the night, or sometimes something happened, when you walk into the house and you want to tell somebody and there’s nobody here to tell.”

“I like the company of them coming into my home and I feel she’s part of it now...I wish she had more time.”
“...all you’re not in control of your health because things happen to you...I think it’s important that you do make your own decisions but at the same time you have to listen to a professional, that’s what they’re there for.”

“I like to be known by my name and not that old woman.”

“I just have the television for company.”
are and support:
Both the orsho and the inter ie artici ants e hasised the social as ects of care in addition to the ractical co onents eo le often descri ed their satisfaction or dissatisfaction ith their care in ters of ersonal relationshi es rather than the actual care that as eing deliered
It is i orta nt to note that the older eo le es o e to did not generally dra a distinction etween health and social care su ort; they sa their su ort as one entity
There appeared to e li ited a areness or discussion of for al care lans and although so e inter ie ees said that they had thought a out the future, this as seld o ith regards to ad ance care lanning or end of life care ost artici ants referenced the future ith regards to lans in lace for su orting fa ily in their a sence, funeral arrange ents, or ere generally as an ine ita ility o er hich they had no control, and therefore a desire to ‘ta e one day at a ti e’
To su arise hat asi ortant in ters of care and su ort, the surve y and or sho artici ants found the co osite state ents fro the e isting narrati e every useful, hence these ere carried into the care and su ort section of this narrati e

Terminology:
There ere i ed ie s on the ter s ‘old’ and ‘elderly’, ut ‘frailty’ as alost uniersally re ected Though there as so e sense that it could e recognised in others, eo le did not see it as a way to descri e the sel es

Commmunity Interactions
“I miss social interactions. I don’t mean going out whatever, I mean having a good conversation.”

Development of the statements
The I state ents ere initially draft ed y the steering gro u around the a o e ey the es that e erged fro the literature re ie , the surve y and the orsho s— ut ith articular reference to hat the older eo le e inter ie ed descri ed as eing ost i ortant to the
The narrati e as then re ie ed, re ised and eried through further discussions ith older eo le The gro u felt it as essential to ensure that the narrati e reected the ie s of older eo le and that the state ents resonat ed ith the
...a narrative for co-ordinated support for older people

Using the I statements

The research conducted for this narrative illuminates the challenges of long-term conditions and frailty from the perspective of older people with care and support needs. This poses some key challenges for health and care services:

- Independence: Although older people want to feel supported when they need it, they also want to retain their independence. The value of care and support is that, as the I statement says, it helps to live the life they want to the extent of their abilities. This can present a challenge in that rehabilitation services are often stretched and there can be a perception that it is easier for staff to ‘do something to’ a person rather than encourage independence.

  - Social support: The research has also highlighted the importance of social support — both as part of their community and also in relation to feeling that they have a personal and social relationship with the health and care professionals. This results in an erosion of the independence that older people and their families, those in contact with older people, and informal carers in support of the person.

  “I’m independent because I’m living my own life in my own home and I love it. I’m ninety-two and I can still do that. I call that independence.”
It is intended that these statements will be used to encourage health and social care services to or together to focus on the outcomes that are important to older people in their population. We would encourage older people within health and social care services to reflect on the issues identified in the statements. For example:

- enabling people to maintain independence
- enabling older people to build and maintain relationships with their professionals and practitioners
- to reach out to people in ways that are not easily dominated by ‘eats’ management’ considerations
- to work in harmony and in informal carers and supporters

Health and social care services should also reflect on whether they are measuring what is important to older people. For example, maintaining independence and social interaction are recognised in social care, but are less likely to be seen as outcomes which ainstrea health services and practitioners judge their success. This will have to change.
The ‘frailty’ challenge

As discussed in the introduction, there is an ageing population, and across England local areas are prioritising care and support for older people. To help identify older people at risk of poorer health outcomes, considerable effort is not into better defining ‘frailty’, in the hope of managing it as a long-term health condition. The British Geriatrics Society (BGS), in association with Age and the Royal College of General Practitioners (RCGP), has produced guidance on recognising and managing frailty outside of hospital.

One feature of frailty is that it describes a person at a higher risk of a sudden deterioration in their physical and mental health. This will include older people who could otherwise be referred to as vulnerable users of health services. It will also include older people who require high levels of support and are at the end of their lives.

Recognising a spectrum of need that crosses rather than duplicates long-term conditions management is important. This means that having frailty in mind when identifying, assessing and planning care needs is vital to achieving better outcomes for older people and re-enters the need for crisis and emergency care.

The foundation of good practice is to ensure that frailty is identified as a trigger so that older people are referred to in a way that is acceptable to older people and is endorsed by health professionals. Health commissioners, practitioners, and services are encouraged to est a frailty strategy that is being reflected in the care they are delivering. Older people are therefore issuing a call for a national dialogue on frailty: This research has focused on recognising older people at risk of frailty, and it has reminded us that the older person’s perception of what constitutes good health or frailty is often very different to the clinician’s.

Elderly patients with a number of health conditions, who had previously been described as frail, did not associate the terms as such, and wanted to be supported to have independent living.

Significantly, older people have told us that they do not like the terms ‘frail’ or ‘frailty’ and very few described themselves using these terms. In fact, this narrative was originally a way of capturing older people’s views and was soon dropped in the face of its rejection by the elderly.

It raises us with a dilemma. How do we ensure that we identify frailty as a trigger so that older people are referred in a way that is acceptable to older people and is endorsed by health professionals? Health commissioners, practitioners, and services are encouraged to establish frailty strategies that are being reflected in the care they are delivering.

It is vital that this conversation continues to be led by the views of older people.

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http://www.ageuk.org.uk
The challenge of defining frailty

This is a study. Can may have been described as frail by clinicians. When we met him he was 86 years old and had a number of comorbidities and was close to the end of his life passing away just a few weeks later... however he did not identify himself as being frail. He lived alone with only domestic assistance. He used an iad and went to Pilates classes twice a week. He described his health as ‘pretty good’ and said that independence to him meant ‘doing things for others’.

Picture courtesy of the Heel Heelstead Gazette. Any thanks to John’s daughter for her kind permission to share his story.
Cartners is a leading academic health science partner that supports the healthcare system serving over 10 million people in London, Hertfordshire, Bedfordshire and Essex. Eater organisations from higher education and the NHS have come together through Cartners to improve health outcomes and create health for the local population at scale and across the site www.uclpartners.com

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National Voices is the national coalition of health and social care charities in England and together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that or for the

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Age UK is the country's largest charity dedicated to helping everyone at the end of life. The older is the fastest growing group in society, and there are more of us than ever before. E care services and support at a national and local level to inspire, enable and support older. E stand up and see for all those who have reached later life, and also protect the long-term interests of future generations.

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