



# External Report: Development of a multi-agency, multi-disciplinary action-learning programme based on ‘story-telling’ learning from patients, carers and staff

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## 1 Plain English Summary

People listen to stories. Stories can “change hearts and minds, and cultures and policies” (participant 4, focus group 1). The power of stories to influence how people think about health and social care (HSC) is clear, perhaps because of the powerful and direct way stories help stir the thoughts, emotions, and experiences of people accessing or delivering HSC.

HSC have historically been rather separate from each other, making for a more ‘narrow’ provision of care offered to patients, their carer(s) and family; along with the cost implications of such fragmentation. Because of this, NHS England is working together with a number of national partners in helping to join-up (integrate) the way in which services are delivered in HSC. HSC is highly complex, with many different professionals working in different ways but all for the benefit of the patient, their carer(s), and their family. Because of this complexity, research is required that uses not only numbers (a ‘hard’ approach) to quantify information, but also a ‘soft’ approach that draws upon the personal experiences of carer representatives and HSC professionals, to improve integration of services and support carers.

The Centre for Health and Social Care Research at Staffordshire University worked as the research partner, to support NHS England, in evaluating the ways in which examples of integrated care have led to changes for both carer representatives and HSC professionals. We were particularly interested in exploring the toughest challenges participants faced regarding the integration of carer support services, and what type of integrated changes would make the biggest difference to enabling support for carers. We were also interested in exploring what needs to go right for an organisation to support integration of services, along with how participants felt contributing to the research project.

Four focus group discussions were conducted with total of 22 participants (carer representatives and HSC professionals). We also collected 26 narratives submitted by individuals across Shropshire, interested in sharing their experiences of integrated care and support for carers. Information from the focus group discussions and narratives was explored and analysed to find key themes indicating similarities and differences of opinion between participants.

Overall, findings suggested that carers felt that when services (and HSC professionals) work together for the benefit of the patient, this led to care being more effective in terms of reducing costs and also meeting the patient’s (and carer’s) needs. Carer spoke of the daily challenges, stresses and strains they faced when providing care to their loved ones, and the positive effect on their health and well-being of having their needs listened to and assessed by HSC professionals. HSC professionals highlighted the difficulties they faced in promoting integration of services and working together with other diverse teams. There was a ‘workforce culture’ element serving as a barrier for HSC professionals to work in an integrated way, with HSC professionals preferring to work independently (‘silo’ working) within their own area of speciality. However, both carers and HSC professionals agreed stories could enhance the integration of services, and promote patient-centred care and support.

## 2 Glossary

<u>Term</u>	<u>Explanation</u>
<i>Action-learning</i>	A way of working that aims on solving problems through actions and reflecting upon results.
<i>Assurance framework</i>	A structure by which a health or social care organisation can assess the extent to whether it is achieving its principal objectives and to plan for the future in an objective and proactive way.
<i>Co-production</i>	Collaboration between decision-makers, service providers, and service users to create (co-produce) solutions and services that benefit all.
<i>Commissioning</i>	Within health and social care, the planning, agreements, and monitoring of services.
<i>Focus groups</i>	Group interviews where participants are asked regarding their perceptions, opinions, beliefs, and attitudes towards a focused topic of discussion.
<i>Integration</i>	The way in which organisations, and HSC professionals within those organisations, work together for the benefit of service users.
<i>Local Authority</i>	An administrative body in local government typically comprising a county council and district council.
<i>Multi-agency</i>	Cooperation between several organisations.
<i>Multi-disciplinary</i>	Referring to multiple professional specialities.
<i>Qualitative analysis</i>	A specific way of working with narrative data that emphasises coding information and then interpreting that information in context.
<i>Research methodology</i>	A way of making sense of information through familiarisation and analysis.
<i>Stakeholders</i>	Individuals with a specific interest or concern, in this case, carer representatives and HSC professionals intent on improving the quality and provision of care and support.
<i>Story-telling</i>	A process of conveying events in words or images to promote engagement of others and learning opportunities.
<i>Triangulation</i>	A way of checking whether information is logical or factually sound by using multiple sources of data to assess the same question.

### 3 Executive Summary

The power of stories within health and social care (HSC) is evident through the way stories help to contextualise and crystallise the challenges and experiences of carers, patients, and HSC professionals. Stories have been utilised, in a number of ways, within HSC for many years coming into fashion and falling out of fashion with the passage of time, governmental focus, and demands imposed on the HSC system. Haigh and Hardy (2011) reviewed the role of story-telling within healthcare and found that stories have been used to share health-promoting information across cultural groups; to reach out to marginalised community members to signpost them to health resources; and to help develop forums for people with similar health conditions to support each other. The essence of this review suggests that patients and service users are a valuable source of healthcare-related information and that HSC professionals need to attend to their experiences in the shaping of HSC services (Haigh & Hardy, 2011).

As part of the development of a multi-agency, multi-disciplinary action-learning programme, story-telling was utilised as a research methodology in both the qualitative analysis of focus groups (4) and narratives (26) of key HSC stakeholders, comprising a mixture of carer representatives and HSC professionals. The aim of this programme was to explore how co-production may inform collaborative decision-making and joint planning for carers. The focus groups orientated to determining current stakeholder practices regarding carer support, along with ascertaining perceptions that may contribute to the development of a multi-agency way of working framework, and whether this methodology could be utilised for the development and generation of evidence.

A total of 22 participants contributed to the 4 focus group discussions, and along with the 26 narratives submitted by a range of carer representatives and HSC professionals, inductive thematic analysis was used to qualitatively analyse data.

Findings from the focus groups indicated:

- A variety of challenges pertaining to the integration of carer support services, both for carers and HSC professionals.
  - Carers:
    - Carers having to adjust, often suddenly, to their role as a 'carer' which had implications on how they perceived their identity and were able to seek help and support.
    - The powerful role carers' stories have in the development of evidence-based HSC was clear, but there needed to be sufficient opportunities for carers to 'voice' their story to share their experiences and help others; one of the facets of carers' experience of co-production.
    - The way information from carers is shared between HSC professionals' needs to be more efficient and consistent.
  - HSC professionals:

- Challenges involved in trying to change a culture of risk-averse professionals, embedded within a bureaucratic system of working, with limited finances to make meaningful changes to the patient and carer experience.
- Carers and HSC professionals considered positives of integrating carers support services:
  - Carers:
    - Aspects of integration of services that resulted in cost-effective and innovative approaches to care. Furthermore, when care services integrated more with each other (including HSC professionals within services), this resulted in cohesive and shared care planning that met the patient's needs.
  - HSC professionals:
    - Discharge planning from hospital was a key example of integrated working, and being able to feel confident in sharing knowledge, skills, and experiences with colleagues across the HSC workforce. This was especially important, given the complexity of the HSC economy, and in needing to provide care and support for patients with ever-more complex long-term health conditions, and carers who are constantly striving to achieve a delicate balance between providing care for their loved ones' and themselves.
    - Co-production was an important and evolving aspect of the HSC economy, and that further work in establishing the effectiveness of using patient stories to influence decision-makers, was required. It was clear that story-telling and carer involvement at board level can readily be used as robust evidence-base alongside other more objective ('hard') sources of data, such as statistics and measurable outcomes.

Findings from the narratives reiterated:

- For integration to be successful and to add to the patient and carer experience, there needed to be much better consistency between services.
- Communication processes between HSC professionals within and between services needed to be monitored and improved where necessary. Compounding matters further were considerations regarding the challenges of contracting care to private agencies.
- Carers were highly resilient individuals, but were surviving under an immense degree of stress and risking 'burnout'. Carers may also not often realise the degree of stress they were under until they are offered care and support.
- Carers sometimes felt they were not an active part of their loved one's care and support and lacked a voice in being able to influence decision-making.
- Some carers did not identify themselves as 'carers' until they were made aware of the extra help and support they were entitled to. The importance was in ensuring that adequate assessment of needs takes place and the necessary psychosocial support is provided at the point of

need. This was significant given the complexity of care carers' loved one's required to meet their activities of daily living.

Findings highlight that co-production and story-telling has been an important aspect of influencing decision-making within HSC. Considerations regarding the development of a conceptual framework for carer support are offered and emphasise, that whilst the integration of services is beneficial for carers and HSC professionals on a number of levels, there needs to be sufficient consultation on what 'integrated care' comprises to both carers and HSC professionals. Furthermore, considerations are required as to lessons learned from previous integrations within HSC.

## 4 Introduction

*“We are sick of falling through gaps. We are tired of organisational barriers and boundaries that delay or prevent access to care. We do not accept being discharged from a service into a void. We want services to be seamless and care to be continuous.”* (National Voices, cited in National Collaboration for Integrated Care and Support [NCICS], 2013).

The above quote represents the collective voice of patients and carers through 130 health and social care (HSC) charities. This narrative highlights potential missed opportunities to prevent or delay the onset of HSC needs, along with fragmented provision of HSC that may not necessarily reflect person-centred care. The NCICS (2013) go on to state that fragmented care and support also has further deleterious consequences such as, repetitive uncoordinated care, multiple hospital visits and admissions along with emergency readmissions, and unsafe transfer of care between hospital and home.

‘Integrating’ care and support is considered a way of addressing these challenges and improves the effectiveness and safety of care along with the patient experience (NCICS, 2013). However, the term ‘integration’ is open to interpretation, meaning different things to different people, with no single ‘best practice’ model of integrated care (Goodwin et al., 2012). Despite this, integration is generally considered to represent the *processes* of collaboration between the organisation and the HSC professionals working within that organisation, along with improving *outcomes* for patients and service users accessing care and support (Curry & Ham, 2010). Whilst this definition appears straightforward, there are different typologies of integrated care that focus on ‘systemic integration’ (coherent rules and policies in the organisation), and ‘normative integration’ (an ethos of shared values between HSC professionals). Curry and Ham (2010) suggest that closer integration of care within the NHS should continue, but should focus on the ‘macro’, ‘meso’, and ‘micro’ levels. The ‘macro’ level focusing on effective leadership and a collaborative culture; the ‘meso’ level focusing on the needs of particular groups of patients and populations (for example, older people, and people with long-term conditions); and the ‘micro’ level focusing on improving coordinated care for individual patients and carers.

Whilst integration is realised in different ways, what does appear consistent is that organisational integration by itself is not sufficient to deliver integrated care (Goodwin et al., 2012). Indeed, the on-going organisational changes in the NHS have been constant in recent times; unwelcomed by clinicians due to the focus on making the NHS more market-like and fragmented, and not allowing changes sufficient time to take effect (Rose, 2015). Furthermore, within social care there is continued fragmentation within social work (for example, as a consequence of the different roles, beliefs, and identities for social work as a profession), along with fragmentation of services (for example, domiciliary, nursing, and residential support services) (Carey, 2014). At the heart of the NHS are its patients and service users (The NHS Constitution, Department of Health [DH], 2013), and in order to achieve

integrated care, it is only right that HSC professionals involve the service user's perspective when planning and providing services (Goodwin et al., 2012). The perspective of a service user as an active participant in their care can be summarised as follows,

*"I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me."*  
(National Voices, 2013, p. 7 & 15).

The notion of integrated care in this context means that care is person-centred and coordinated (National Voices, 2013). An intrinsic part of this care provision is in making sure that the service user's needs are *assessed*; that their carer(s) and family needs are *recognised*; that they are *supported to understand choices* open to them; and that the care and support offered helps them to feel *empowered and valued* (National Voices, 2013). This is a pressing issue given the National Carers' Strategy (HM Government, 2008) states that, as more people are living longer and developing long-term conditions, there is a higher demand for care to be provided by family members. The importance of family carers maintaining a positive work-life balance whilst providing care to their family or friends has never been more important. Therefore, the focus of the National Carers' Strategy is to prioritise the needs of carers and provide them with the recognition and status they deserve (HM Government, 2008). Essentially, care needs to be more proactive rather than reactive, more holistic rather than episodic, and more focused on the interrelationship between health and social care (NHS England, 2013a).

Although the National Carers' Strategy (HM Government, 2008, p. 9) states that by 2018, carers will be, "universally recognised and valued as being fundamental to strong families and stable communities", many challenges still exist to facilitate this. One of the challenging attempts to make care more integrated are the 'permission-based' and 'risk averse' NHS management approach; divisions between primary and secondary care, and between HSC; time restrictions and threats to sustained project management; absence of robust shared electronic patient records; and persisting weakness of commissioning (Goodwin et al., 2012). If the vision of the National Carers' Strategy (p. 9) of having carers as,

- "expert care partners;
- [being able to] access integrated and personalised services;
- having a life of their own alongside their caring role;
- [supported] so that they are not forced into financial hardship by their caring role;
- supported to stay mentally and physically well and treated with dignity"

is to be realised, then there has to be a radical rethink of the way family carers are perceived by HSC professionals, along with significantly more collaboration between HSC professionals and carers. There are bound to be challenges in addressing the National Carers' Strategy, but a starting point to overcoming such barriers is in the,

*“crafting of a powerful narrative at both a national and local level about how services could and should be delivered for people with complex conditions ... [and] a clear articulation of the benefits to patients, service users and carers.”* (Goodwin et al., 2012, p. 8).

Through ‘integrated care pioneers’, NHS England (2013b) has already started the process of exploring various ambitious and innovative approaches local authorities and clinical commissioning groups have used to deliver person-centred, coordinated care and support. However, determining the impact of these initiatives is complex because of the time (often years) it takes to develop integrated services, and the fact that transformation from fragmented to integrated care is rarely linear (The King’s Fund, 2015). This action-learning programme explored at a local level (Shropshire) whether and how integration of HSC has worked for HSC professionals, along with patients and carers. It also explored the values and benefits of using a model of co-production to capture stories and narratives as a valuable source of evidence to shape and inform services. Some recommendations for all the stakeholders in this collaborative project are also proposed.

#### 4.1 Aims

To explore how co-production may inform collaborative decision-making and joint planning for carers, with a particular emphasis on using stories/narratives (with a focus on integrated services) as an evidence base.

#### 4.2 Objectives

- Ascertain current stakeholder’s practices with regards to carer support.
- Review and triangulate current evidence and data sources that are used and captured by key stakeholders.
- Capture stakeholder experiences of collaborative working in order to develop a guide to be used by HSC areas to learn from the approach.
- Demonstrate if co-production is a useful method for the development and generation of evidence.
- Identify whether collaborative working with key stakeholders can contribute to the generation of evidence that can be used to inform on-going development of a combined health and social care (HSC) multi-agency assurance framework.

## 5 Methodology

### 5.1 Design

A qualitative methodology was utilised for the collection and analysis of data. A series of 4 audio-recorded focus groups were conducted; 2 on 11/11/15 and 2 on 12/11/15. A focus group interview schedule, comprising 7 questions/areas for exploration (Appendix A), was created during the planning of the project. Key stakeholders also submitted a total of 26 narratives for analysis, facilitating the triangulation of evidence, exploring how co-production might inform collaborative decision-making and joint planning for carers. The triangulation of evidence also led to the formulation of a variety of recommendations offered for all stakeholders in this collaborative project.

### 5.2 Participants

A total of 22 participants comprising both carer representatives and HSC professionals (current and retired, some also carers themselves) contributed in the focus groups lasting on average 50 minutes. Participants worked for a number of HSC key stakeholder partners, summarised in Table 1 below according to 5 main categories.

Table 1: *Participants' organisation categories (focus group interviews)*

<b>Organisation Category</b>	<b>Number of Participants</b>
Local authority (LA)	14
NHS	4
Charities	3
Dementia training	1

LA included agencies managed by the local council, for example, Carers' Partnership Boards. Participants working for the NHS were either clinicians or commissioners or carer representatives involved on patient, involvement, and engagement panels. Charities comprised community organisations and a volunteer HSC network.

### 5.3 Ethical considerations

Ethical clearance was obtained through 'Proportionate Review' from the Faculty of Health Sciences Ethics Panel (Staffordshire University). A letter was received from NHS England indicating that this was a service evaluation.

Participants were issued with an information sheet detailing the purpose of the study, issues of confidentiality and data protection. Participants were informed their participation was entirely voluntary and they could withdraw from the study at any point without question. Participants signed a consent form, stating their organisation, prior to taking part in the focus group interviews. After each of the focus groups participants were thanked for their time and for sharing their experiences of integrated care and support.

## 5.4 Co-production

From the outset of the project it was clear that stories and narrative data would be valuable sources of information. NHS England noted that valuable insights were gained from conversations at national summits, highlighting the necessity to harness the carer voice as evidence to drive the integration of service provision so carers can experience smooth transitions of care and easy access between services within HSC.

Co-production refers to the processes of collaboration between decision-makers (for example, NHS commissioners), service providers (for example, HSC professionals), and service users (for example, representatives of patients and their family carer[s]) to create a decision or service that works for all concerned (NHS Institute for Innovation and Improvement, 2013). What makes co-production useful, as a research methodology, is its focus on action learning, based in the values of all who collaborate, along with the notion those who are affected by the service are often best placed to design it (NHS Institute for Innovation and Improvement, 2013).

The Social Care Institute for Excellence (SCIE, 2015) highlight the complexity of trying to define co-production, but emphasise the need for organisations and projects to come to an agreement on what they understand co-production to be. SCIE (2015, p. 5) suggest that co-production focuses on:

- Service users as “assets with skills”.
- The “breaking down of barriers” between service users and HSC professionals.
- “Building people’s existing capabilities”.
- “Reciprocity (people getting something back for having done something for others) and mutuality (people working together to achieve their shared interests)”.
- “Peer and personal support networks alongside professional networks”.
- “Facilitating services by helping organisations to become agents for change rather than just being service providers.”

It became clear to the research team, in collaboration with NHS England, that co-production was an essential aspect of the project’s methodology due to the inherent complexity of promoting the integration of services for carers. As such, we needed our ‘participants’ to be equal partners and co-creators<sup>1</sup>. The SCIE (2015) highlight that co-production refers to this notion, as opposed to participation which refers to people being consulted with.

The research team’s role was to provide research expertise and methodological support to NHS England, who were working as the key organisation to oversee co-production with key HSC stakeholder partners; driving the integrated commissioning of services between HSC.

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<sup>1</sup> SCIE (2015, p. 6) further distinguish co-production as, “people who use services taking over some of the work done by practitioners” [potentially Carers’ Partnership Boards], compared with ‘co-creation’ which refers to, “people who use services working with professionals to design, create and deliver services.”

## 5.5 Data analysis

Focus group interview audio recordings were listened to and pertinent parts were transcribed verbatim. The 26 narratives submitted were analysed in their original form. Inductive thematic analysis (Braun & Clarke, 2006) was used to identify, analyse, and report patterns and themes within the data, focusing on themes that were strongly evidenced by the data itself (Patton, 1990). For the focus group interviews, these provided insights into the challenges participants faced regarding integration of carer support services, and the range of actions required that would bring about positive change. For the narratives, insights were obtained from the way HSC professionals provided integrated care and support for patients, carers, and their family, along with powerful examples (positive and negative) of care received by patients and carers.

Inductive thematic analysis can be summarised in three phases (Figure 1) and in more detail in six phases (Figure 2).

Figure 1: *Three-phase inductive thematic analysis summary*

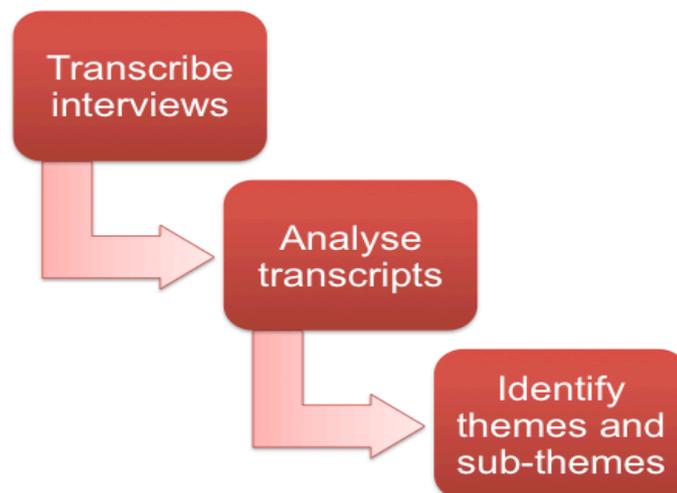
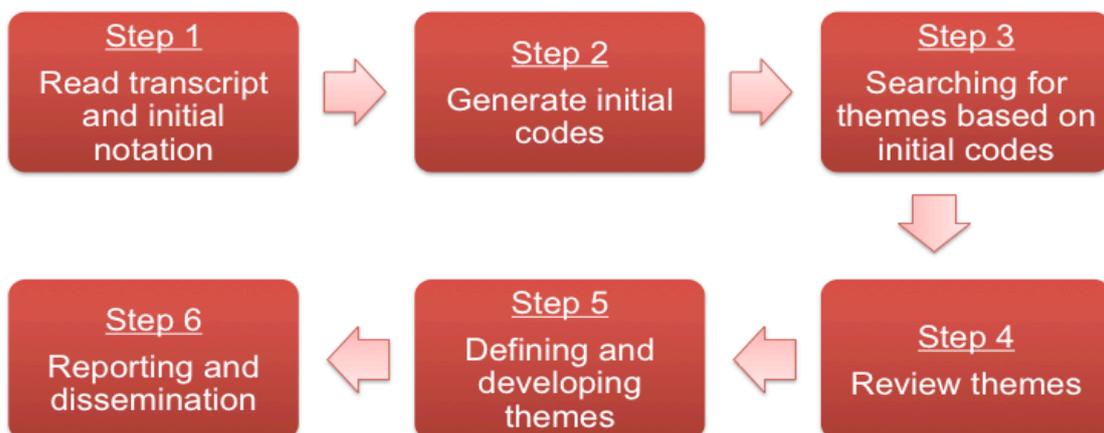


Figure 2: *Six-phase inductive thematic analysis*



## 6 Findings

Findings from the focus group (FG) interviews and narratives are presented separately, but will be discussed together (in the discussion).

### 6.1 Focus group interviews

Findings from the focus group interviews are summarised under 3 main themes and a number of subthemes (Table 1), according to whether the focus pertained to carers or HSC professionals.

Table 1: *Focus group interviews qualitative themes and subthemes*

Theme	
Toughest challenges for integrating carer support services.	
Carers	HSC Professionals
Challenges of adjustment	Organisation barriers: Culture
Information sharing	Organisation barriers: Bureaucracy
Providing person-centred care	Organisation barriers: Funding
Theme	
Examples of integrated changes	
Carers	HSC Professionals
Cost effectiveness	Discharge planning starts on admission
Having a cohesive (integrated) plan	Using everyone's knowledge and skills
Theme	
Experience of co-production and story-telling	
Carers	HSC Professionals
Sharing and helping others	Promotion of story-telling
Having a voice	Evidence-base

#### 6.1.1 Toughest challenges for integrating carer support services

##### 6.1.1.1 Carers: Challenges of adjustment

In FG 1, one carer explained that the failure of adequate integration of support services, despite their proactive approach in their son's care and knowing what to implement for the best of the family, was nearly catastrophic for the family.

*"As parents, [the events] nearly took us to breaking point ... bad experience when son first went into care ... school finding [care] difficult to handle ... [son] needed different types of schooling ... end up becoming residential [care] as well ... within about 2 weeks, [son] literally went from that school straight into residential care alongside school on site ... very difficult time for [family] as no time to adjust, it just happened."* (FG 1).

The relatively sudden transitions of care, highlights the need for organisations providing care, whether it be a school or otherwise, to effectively risk assess

and have contingency plans in place when required. Clearly, the family carer(s) need to be actively involved in such discussions. The stresses for family carer(s) also persisted, as the participant explained further the challenges of their son going from children's to adult services.

*"[On son's] 17<sup>th</sup> birthday, [family] decided we would start looking at [future planning] ... realised very quickly there was a lack of [care] placements ... [son] would end up with a place outside of the county ... with 2 children with learning difficulties ... how would we manage, function as a family ... one point [the LA] stated [son's care] was with children's services, then [son] turned 18 [years], now [care] with adult services, so children's services stopped talking to me and it was adult services. Before that only children's services talked to me but not adult services ... we needed both to talk to me for transition to happen ... massive frustration." (FG 1).*

This participant's (and their family's) priority was for the well-being and safety of their son, moving between care services. On the whole, it appeared mainly irrespective which service was facilitating care and support for their son, as long as care and support was being provided. Undoubtedly, if both children's and adult services were collaborating more effectively with each other, and involving the family carer(s), this would have likely eased the transition and reduced the challenges of adjustment for the family.

To facilitate their son's care, the family ended up purchasing another property (where their son's care was provided from), but encountered challenges with the LA in arranging this new care plan.

*"Process [with the LA] taken nearly 2 and a half years ... everyone understood and said it made perfect sense, but [this has] never been done before [LA] not sure how it's going to be done, who to speak to about this ... how do you get the right people [responsible] to be able to discuss and do that?" (FG 1).*

This illustrates that both family carer(s) and LA's strive to collaborate in the interests of the service user, in this case this participant's son. However, the threats to effective collaboration which result in meaningful differences in the care provided appear to be in the 'risk averse' nature of authorities working outside of conventional protocols and also in organising meetings with the necessary stakeholders.

Another participant (an NHS commissioner) in FG 1 echoed other focus group member's respect for the previous participant in coping with the challenges of adjustment, and trying to get their son the right care at the right time, emphasising the importance of decision-makers learning from this story.

*"It's about influencing decision-makers at the end of the day ... even people who are not involved like ourselves, feel your frustration ... why can't people see that this is the way forward without having ... bureaucracy or people not talking to each other ... service users, carers stories, staff stories, they can be*

*really powerful ... why can't [they] be used in decision making bodies?" (FG 1).*

#### 6.1.1.2 Carers: Information sharing

Although carer's stories are very powerful and could be used as a robust evidence base to influence the commissioning of services, decision-makers need to remain aware that carers may struggle to share their experiences for a variety of reasons.

*"[Carers] have to organise absolutely everything to go in [to facilitate care] ... what I did for my mum ... she was 96 [years old] with Alzheimer's, registered blind, disabled and urinary incontinent ... managing her in her bungalow ... done that for 8 years ... I gave up my teaching job, my career, I look after my mum because I am the only sibling ... through teaching and trying to look after my mum I developed atrial fibrillation ... extremely, extremely difficult ... I know people want to hear my story ... this is as far as I can get because it's so emotional and it's so raw that I haven't managed to do it yet ... people in the community I've met at day centres who take their loved-one along, they're in a much worse position than I am, they just keep going on ... [but] you do [as carers] feel so along." (FG 2).*

The emotional 'rawness' of the situation, not to mention physical health conditions that carers might develop, can present as a challenge to sharing their story with decision-makers. An illustration of the utility of this particular focus group (and project in general) was in the opportunity it created for this participant to voice their thoughts and feelings of being a carer for their mum. This is an opportunity that might have been denied without a focus group discussion or some other method of sharing experiences in a safe and supportive environment.

The excerpt above also highlights the extent of the challenges carers face in providing on-going care for their loved ones, which is most often out of love and not duty. Carers' resilience is testament to their ability to provide care in the face of challenges such as leaving their career, or persevering with physical health problems associated with the stresses of caring. However, there are times when carers are genuinely 'fatigued' in sharing their stressful story.

*"From a carer's point of view it's how many times ... (my mother has dementia) ... you have to tell your story to health professionals, social care professionals, [as] power of attorney you're doing that ... you've got to repeat it, it doesn't seem that people communicate between health and social care ... makes it quite stressful [to repeat information]." (FG 2).*

Clearly, one of the ways in which carers would be assisted to not have to constantly repeat information, would be if various services in health and social care had methods and protocols of sharing that information in a specific, relevant, and timely way. However, even if there are methods of sharing

information, the accuracy and validity of that information might be compromised if there is a breakdown in communication from the outset.

*“It’s people’s ability to listen to what you’re saying. I may have said something to the nurse from the memory clinic and she may have passed that on to a consultant ... and it comes back that she’s misinterpreted what you’ve said ... it’s the pathway for information, listening accurately and passing that on.”* (FG 2).

The validity of information might also be further compromised when service users have complex health and social care needs and are being supported by multiple agencies simultaneously. This puts further stress on carers who, in their frustration and fatigue, find ways of coping with this.

*“[As a carer] I was constantly repeating what my father’s ailments were, what medication he was on, what he suffered from and he had quite a lot of illness over his life. There never seems to be any joined-up [care] when you go from one service to another because he had other problems ... in the end I had a ‘script sheet’ ... that was the only way I could cope with it.”* (FG 2).

#### 6.1.1.3 Carers: Providing person-centred care

It is reasonable to infer that carers’ resilience, and faith in health and social care services, will be maintained in the knowledge that person-centred care is being provided to their loved ones. However, when care is not orientated to the person’s needs this produces unnecessary stress both for the service user and their family carer(s).

*“My husband was in care and he’s got dementia, his swallowing went, he was on puréed food. [The carers] were sending up steak and kidney pudding, mashed; potatoes, not puréed. I asked the home if they could improve on this and they didn’t. So I rang the SALT [speech and language therapy] team and they were there within a couple of days ... interview with [SALT] and the chef who denied ... he wasn’t there when it happened and they wouldn’t have sent up steak and kidney pudding. The SALT team acted very promptly and things were sorted out ... the thing is, I’m capable of looking after myself, not everybody is, and if I hadn’t have known where to get the help, which a lot of people wouldn’t know, it could have been nastier story.”* (FG 3).

This story illustrates that the provision of person-centred care need not be complex, and that if this person’s needs were adequately assessed and communicated to others within the same organisation, then errors – which could otherwise in this case be life-threatening – would be easily avoided. Perhaps what is more concerning is that, in the case above, the carer’s concerns appeared to not to have been acknowledged or acted on by the organisation, such that this led the carer to approach a specialised team (SALT) for support. Although this story illustrates that effective integration between services, in this case between the care home and SALT, led to a

positive outcome for all concerned, it does highlight that this should not really have been left to the carer alone to address. As the carer stated, there would likely be others (carers) who would not know where to turn to for help and support. It is really up to organisations and their health and social care professionals to effectively assess service users' needs and provide care that is personal and safe.

There is a vital need for organisations and their staff to involve family carer(s) in service user assessments. Sometimes, service users might be unable to voice their concerns or express the degree to which care would be personal to them. Family carer(s) can provide information for any of the missing links, and it is important for organisations to consider the broader needs in facilitating person-centred care.

*“[Providing person-centred care] is about other aspects ... look at what [my son] would miss out on in terms of his family, his brothers growing up, his community, we're quite close with the church, all of that. None of that is taken into consideration.” (FG 1).*

As such, the provision of person-centred care implicates the service user along with their wider family circle, friends, and sometimes their community. If a service user suffers, chances are significant others will be suffering also, and vice-versa.

Collaborative working and integration of services has the potential to enhance the transitions of care offered to service users and their families, promoting effective communication and person-centred care. However, the process of integration is not an easy one, as a participant describes below.

*“One of the problems is that integration and proper partnership working actually requires time, you need time to talk to other people and get to know who's who in any kind of network or circle of care. Professionals like GPs, district nurses, hospital staff are under such enormous time pressure, and I think there has to be recognition that to make systems work in an integrated way, professionals (the clinicians), they need time for those conversations and relationships to develop and be maintained, and to be conducted in a way that enables meaningful collaboration.” (FG 2).*

#### **6.1.1.4 HSC professionals: Organisational barriers (culture)**

For service users and carers, transitions between services will likely not be gradual, nor will information be shared effectively, or person-centred care delivered, if there are fundamental organisational barriers in place. A participant in FG 1 highlighted that fundamental cultural change throughout the NHS is required to address these organisational barriers to integrated care and support.

*“It’s a lot of breaking down barriers, making some cultural changes to very historical practices, procedures, policy that is governed by, especially in the NHS, litigation.” (FG 1).*

This excerpt echoes the challenges that another participant (carer) in FG 1 faced when trying to get the LA, over a period of 2.5 years, to embrace a different way of providing person-centred care for their son. Organisations risk-averse approach to integration of services appears to manifest in not only the notion of integration being relatively unknown or untested territory, but also in the fear of having lawsuits filed against the organisation if something goes wrong.

*“Litigation is on the increase ... fearful culture that if they don’t follow a procedure or process ... health and safety is governing a lot of that ... people forget that they don’t need permission to question why do we do that, is it right, could we do it differently?” (FG 1).*

Whilst there appears a possibility that there will *always* be a degree of ‘fear’ in organisations regarding potential lawsuits against them, a subtle suggestion is made, that empowering HSC professionals might be a way forward to drive the integration agenda. When HSC professionals feel able to challenge current practices and consider new ways forward, it is plausible that they will be drawing upon the knowledge and skills of their colleagues and other teams. However, this is not a straightforward process and often it appears that HSC professionals tend to feel more comfortable with the familiar rather than unfamiliar.

*“Breaking down the barriers is easier said than done because people do work in silos as well when you try and integrate and engage with people from different services. Everyone has their own policies and procedures to follow ... [however] you can break those barriers down without any harm.” (FG 1).*

An associated consideration by another participant in FG 3, illustrates that silo working may be due in part to organisational change in general along with the uncertainty HSC professionals face regarding the longevity of their position.

*“Changes to departments and staffing, obviously that’s quite big [an issue], just when you’ve got those contacts, and those services in place they may change, the staff may change and it’s keeping on top of those things.” (FG 3).*

On-going reorganisation of services not only leads to challenges for HSC professionals keeping up-to-date with service developments and working collaboratively, but also may lead to an unwanted reassessment of priorities for the service.

*“Carers generally [can] sometimes [be] a lower priority on people’s list of things-to-do and focus on ... because the health*

*professional may have such a focus on the patient and also just the medical model being such a focus by the healthcare professional and them not seeing the bigger picture ... story about somebody who was told there was no point having a diagnosis of dementia because it wouldn't make any difference [to their care], and this was a GP talking very much about a medical model difference, and not all the things that the diagnosis [of dementia] would open up for that person. ” (FG 3).*

Reprioritising carer support in favour of focusing more on the patient and their problems, as in an interpretation of the medical model, is considered fundamentally flawed, especially as patients with long-term conditions might require on-going care from their family. Essentially, the story above illustrates that HSC professionals need to have not only a broader understanding of their systems of work, but also how their role contributes to the outcomes of care, which need to be focused on not only the patient but “their families and their carers” (NHS Constitution, 2013, p. 3).

#### *6.1.1.5 HSC professionals: Organisational barriers (bureaucracy)*

Health and social care, essentially by definition, is inherently complex and often patients and their family and carers may not be central to the provision and management of care. Part of this issue appears to be in the overemphasis on the systems of work and clinical governance and compliance rather than on assessing whether care is meeting the needs of its service users.

*“Clearly what was not put at the centre was [participant’s] son’s needs. What was put at the centre was: bureaucracy or, ‘we can’t do it, never done it, that risk – it’s too risky’ [attitude]. That’s what was put at the centre. ” (FG 1).*

Bureaucracy was also considered to be a fundamental organisation barrier in integrating carer support services in other focus group, with a pressing need to simplify organisational processes and work from the perspective of the service user, not the strategist.

*“One of the biggest, most important things, especially locally (I can only talk from experience within the organisation), is to break down the internal bureaucracy; the red tape to try and achieve anything. We have to be seen to protect the public purse and everything else but we over-process far too much, and we need to simplify things more and we need to listen more [to service users] ... develop the Health Champion Model ... being out there talking to people, see what people want, not what we as a council decide you want ... value them, give the resource to do it.” (FG 4).*

Working from the perspectives of service users seems a feasible way of being able to simplify, otherwise complex, processes of health and social care, which will probably be more aligned with clinical

governance and compliance rather than person-centred care and support. This 'bottom-up' rather than 'top-down' approach was definitely favoured by another participant in FG 4.

*“Absolutely! You’ve got to start from the ground up as well, not from the top down ... you need a whole range (cross-generational) of people [to facilitate integration of services].”* (FG 4).

Although participants considered reducing organisational bureaucracy was definitely a way forward to enhancing the integration of carer support services, it was not necessarily clear exactly *what* bureaucracy comprised of. This was queried by one of the focus group facilitators (SJS), with reducing bureaucracy considered as freeing-up time to spend with patients and families and raising money in innovative ways. Participants agreed, with one participant eloquently illustrating that the whole process of care is most effective when it is focused on the person and not in creating artificial categories to concord with the processes of the service.

*“I’m sure there’s a lot of time wasted trying to explain why people are exceptions [from receiving services] or ‘complex cases’ – words I absolutely hate – when they’re just ordinary people and their problems need solving ... and the people who are doing this should know the answers or lead them towards the answers.”* (FG 4).

However, the simplification of processes and focus on the person and their needs as they arise may sometimes be at odds with the way HSC professionals are trained and in the time they have to provide that person-centred care.

*“[One thing that would make the biggest difference to integration of carer support services] comes back to the bureaucracy, it’s the one thing we found ... working with social workers, we talk about how we were brainwashed within adult social care, because the social worker pitches up with the form to fill in, and with their pen poised, instead of just having a human conversation, and using those questioning skills to be able to tease out the answers that are arising out of that situation rather than focusing on the form. That comes down to resource pressures, budget cuts, no staff, bigger caseloads, less time. It’s really tricky.”* (FG 4).

The challenge for HSC professionals appears to be in maintaining their professional integrity and completing what assessments are required, but also in being able to invest time to care and relate to the service user in a 'human' manner; qualities that appear to transcend the processes of assessment and form filling.

#### 6.1.1.6 HSC professionals: Organisational barriers (funding)

The previous participant in FG 4 alluded to the reality that HSC budgets are under constant threat and that the pressure is on HSC professionals to deliver high quality care under considerable financial restraints like never before. Unfortunately, what appears to happen is that the family and carers end up picking up the bill for additional costs associated with providing care for their loved ones that LAs or other organisations cannot cover. This further adds to the stresses family carer(s) incur on a daily basis.

*“One of the changes happening as a result of contraction of budgets ... sometimes it’s implicit rather than explicit ... there’s an increasing pressure and expectation on families around what they will contribute to the caring process and people often aren’t given an opportunity to really articulate what they feel able to manage, cope with, taking account of their own health and well-being ... runs counter to the fundamental principles of the Care Act, and we do need to be aware of that.” (FG 2).*

LAs and other organisations, in accordance with the Care Act (2014), under section 20 (duty and power to meet a carer’s needs for support) have a responsibility to at least assess (explicitly) a carer’s need for support, rather than assuming implicitly that family carers’ will fill any financial deficit. Sometimes, however, when family carer(s) have above a certain amount of finances available, all responsibilities for ensuring care is available along with the associated stresses fall to them.

*“As a self-funder, when someone’s got more than £23,500, that you are totally responsible for the person you are caring for. I managed to get 6 weeks respite for my mother, from home, because I asked for a Carers Assessment, and she got that respite because of me, because of my heart condition, and my husband went into hospital for a hip replacement ... 6 weeks respite care was given. Letter from social services, from social worker ... ‘you are now signed off our books’, because as a self-funder, they only stepped in because they had to, but we’re now off the books and I’m totally responsible for [mother] ... carers are under a lot of pressure and I think that the whole thing needs changing ... the letter states not to contact until [self-funding runs out] ... I have great sympathy for [social services] because they’re working in a system and doing what they’re asked to do, but it’s inhumane and it’s cruel ... voluntary organisation out there that have been absolutely excellent.” (FG 2).*

Whilst from a funding perspective one might argue that if a carer can ‘get by’ and fund whatever care they can themselves, this would be better for the HSC system more generally, the concern here is the apparent lack of future planning and being proactive to ensure there is continuity, and minimising potential stresses for family carers in

knowing that things will be in place to continue providing care when self-funding runs out. This proactive rather than reactive care is often readily acknowledged by HSC professionals in practice but the system of their work does not always facilitate this in practice, as another participant states.

*“One of the biggest problems is that until and unless things are in crisis, there’s often so little for the carers ... professionals in the field feel aware of that, that there is little they can offer and do. Increasingly what little bits [of help] they could offer are being eroded by resource constraints. That does contribute to this disconnect.” (FG 2).*

Sometimes, it might not be the case that the financial resources within the system are not available for use, but rather that services and departments within the organisation perhaps shy away from their responsibilities in providing help and support in favour of protecting their budgets.

*“My concern is the lack of integration and willingness in sharing ‘passports’ and practices is sometimes going to become more so less to do with data protection and confidentiality, and more to do with actually protecting budgets [general agreement of FG]. There is going to be an interest for some organisations to remain hidden and to be difficult to navigate around ... the amount of meetings I have been to talking about CHC (continuing healthcare) funding and on-going debate as to who is responsible for funding this, is it the council, is it health ... less and less incentive for those organisations to promote themselves in the hope that they’re obliged to give.” (FG 3).*

## **6.1.2 Examples of integrated changes**

### **6.1.2.1 Carers: Cost effectiveness**

Within the complexity of HSC there appears an array of examples whereby Healthcare Trusts and LAs might operate under a false economy. They may conclude an apparent financial saving when there is the likelihood of greater expenditure further on in a person’s care. A participant (carer) in FG 1 illustrates this point when they requested the LA and its carers to consider different ways of providing care for their son out in the community.

*“Residential care [would] cost the LA around £150-170,000 per year. The right support now [for son] at a fraction of the cost ... might avoid that [higher cost]. [If it is over] 5 years, that is nearly £1 million. How can that be right?” (FG 1).*

Clearly, HSC commissioners would find cost savings by implementing a different way of working, outside of conventional policy and procedure. Whilst HSC commissioners would likely have to justify the initial costs for a change in care, this could be evidenced against future cost savings, which in the case of the example above would be significant. A participant in FG 2 also highlights

that, despite the additional costs and resources required to conduct assessments thoroughly within an integrated multidisciplinary team, future cost savings not to mention provision of person-centred care is significant.

*“Would be good if [stories] could evidence both time and cost efficiency as well as better quality outcomes ... demonstrating the best case scenarios and best examples of integration ... there are hidden costs ... [previous] example if we worked out the cost of that assessment process, because of its inadequacy, as opposed to a single assessment followed by a multidisciplinary decision-making process, it would be interesting to look at the cost and time difference ... we don’t get the opportunity to do that and we should [have].” (FG 2).*

The excerpt above demonstrates the potential power of story-telling in leading integrated changes in HSC, such that demonstrating cost effectiveness would capture the attention of HSC commissioners who might otherwise have thought twice regarding the utility of stories. However the emphasis, again through the power of stories reverts back to the patient experience, that if in this example, assessments are truly integrated and thorough, this would lead to better care and support. Integrated care would also likely lead to the opportunities in evaluating care processes from multiple professional perspectives, thereby preventing patients and carers from ‘falling through the net’ of care and support. However, time would have to be allocated to such processes of evaluating improvement and quality assurance.

When care is truly person-centred, as well as focused on the family unit, this can also lead to cost savings, even when the provision and management of care is relatively unconventional. A participant in FG 4 shares a story whereby they were helping to change the provision of care around support planning.

*“Creative and innovative support planning that is a lot more person-centred ... commissioned an external company to support and train our own staff with this style of support planning ... worked with Carers Self-Assessment Document ... response that we had from several carers [one being] ... her husband traditionally would have perhaps [attended] day service ... [providing] carers relief ... was not the path that developed for him ... throughout the innovative support planning process we found out about them as a family, what was important to them ... organised different things for him to go off and do various volunteer roles, looking at the skills he had ... giving back to the community ... [also] activities for them to do together, using their local community ... no transport [problems] ... it costed a lot less than the traditional route we would have gone down but the outcomes as well as the cost saving, the outcomes for both people; well you can’t measure [the quality of that].” (FG 4).*

The power of this story is self-evident, that this patient and carer were not being offered a service (day centre), which they could either take or

leave, but rather a service that they could also co-produce with the HSC team. The cost savings of which were evident thereafter. One of the central aspects with this story is that the care is a result of careful assessment and deliberation between professionals and clients. All concerned are very much aware of what the plan is and how this will make a difference in the lives of patients and carers. Having a cohesive plan is critical for both parties in the delivery and management of HSC.

#### 6.1.2.2 Carers: Having a cohesive (integrated) plan

For there to be mutual understanding and engagement to facilitate effective HSC, there needs to be an agreed plan between all parties concerned. A major aspect of formulating integrated care is in the effective communication processes. Stories sharing examples of good communication can be powerful and very reassuring for HSC professionals. However, stories that are not as positive can be very insightful and point towards what could be done differently to support integrated care. A participant in FG 3 shared their story, which illustrated that much more could be done both for their father and themselves as a carer under considerable stress.

*“Was a carer for my father. It’s a very new experience [for me] ... he suffered with pulmonary fibrosis, I cared for him for 6 years ... [father] was taken very poorly ... [admitted to] hospital for 10 days ... [hospital] wanted to discharge him. He wasn’t in a fit state to be discharged and I found myself fighting, constantly fighting his corner ... [father discharged] to community hospital. I thought [the community hospital] would try and get [father] back on his feet because when trying to discharge from [acute hospital] he was still lying in bed on 24-hour oxygen. We weren’t set up for this at home at all. [No rehabilitation] happened [in community hospital] ... communication was extremely poor, extremely poor ... because we live in a rural setting, very little support out there and very little communication between social workers ... just an utter mess really.” (FG 3).*

In the story above, there appears a need for the communication processes to be far more explicit between the acute care hospital and the family, as to what the plan was for this participant’s father. Furthermore, expectations of the family of the community hospital providing rehabilitating for the father were not met, and a need to have a multidisciplinary meeting between HSC professionals and the family was required.

In FG 2, when participants were asked what change they could make to integrated care that would be most effective, a participant highlighted that there needs to be a person responsible for ensuring the coordination of care throughout. In the story above, this was an example of care that appeared very fragmented and could have been much more integrated between acute and community services.

*“It’s about clarity with any particular individual case, who’s coordinating the care and how they’re able to draw together [people/resources] for planning purposes, those professionals who need to be able to contribute. A bit like the team around the child in children’s services, I don’t think that happens effectively in adult services. There must be a way that it could [work more effectively].” (FG 2).*

### **6.1.2.3 HSC professionals: Discharge planning starts at admission**

Sometimes people receiving long-term care and support in the community succumb to illness and require admission for acute care in hospital. This can often lead to significant stress for the patient and family carer(s) and lead to a complete disorganisation of care. This was evidenced previously above in the story from FG 3, where there appeared very little in the way of effective discharge planning and who was leading coordinated care across services (FG 2). Participants in FG 3 considered that from a service perspective, the things that need to go right for integration to happen, is effective discharge planning.

*“Particularly with discharge ... need for somebody across disciplines (hospital, social work, voluntary sector) to take responsibility totally at the point of assessments of need being made ... the power to deal with that person, one person, it could be a doctor, a social worker, a volunteer. Somebody has to take responsibility, because that’s what the fragmentation is all about. We need one person allocated in the case conference to take control.” (FG 3).*

This participant’s (also a carer) story alludes to the notion that, whilst HSC professionals mean well, there can be plenty of mixed messages conveyed to family during the process of discharging a person from hospital back out into the community. This leads to fragmentation whereby, at worst, no one really knows of an agreed plan of discharge for the patient, and at best, care is somehow worked out rather reactively. Another participant in FG 3 stated that failure to plan effectively for discharge from hospital is a sign of ‘organisational failure’ and more needs to be done to support carers (family, friends, and neighbours) out in the community.

*“A more joined-up approach [to discharge planning] in general, perhaps monitoring as to how the care that’s been allocated, how it’s working out, review of that, how it’s been supplemented by the more informal care which sometimes I think is almost not recognised.” (FG 3).*

Another participant (working for a volunteer agency) also noted that discharge planning is about the whole journey for the patient and their family carer(s) whilst they are away from home.

*“[Discharge planning] needs to be at admission and discharge and continuously through that journey and it needs to be mandatory fields that need to be filled in that the carer has been*

*recognised [such as] a name, address, and date of birth on both that admission and discharge.” (FG 3).*

For other participants in FG 2, they concluded that integrated working is most apparent in the processes of hospital discharge planning, where there is a good spirit of collaboration between members of the inter-professional team.

*“Where you see integrated teams being established, like hospital discharge [teams], they all seem to be working really well. You get those multidisciplinary, integrated teams, they are making a difference, and I think that difference is being felt by patients and by the professionals that contribute to that process. I see really good things happening in those contexts.” (FG 2).*

Another participant in FG 2 provided a story to illustrate the result of integrated teamwork.

*“My husband was discharged from [hospital, following] a hip replacement and he had a really good team. There was the physio, social worker, all the different people involved. When he got home, he couldn’t swivel into bed. I rang back the ward and they contacted the community nurse and they came out straight away, we had a visit on the same day, and that [problem] was solve. It was fantastic, everyone worked together and they knew my situation as well. Done in a very caring, very consultative way and done by people who were very professional, the assessments [and so on].” (FG 2).*

What appears to facilitate the processes of integrated working is, not only the process of collaboration and having a person named as responsible for coordinating care, but also the practical consideration of being located with other HSC professionals, as another participant in FG 2 explains.

*“There is something about co-location, about people being in the same place, coming together physically, and when you’re commissioning maybe that’s something that, over time, has to be looked at and given consideration. Key services or professionals [being together].” (FG 2).*

#### **6.1.2.4 HSC professionals: Using everyone’s knowledge and skills**

Having HSC professionals together in the same location can be highly beneficial, not just from the sheer convenience of being able to communicate face-to-face, but also in being able to share knowledge and skills more effectively. When HSC professionals are able to share their knowledge and skills with each other this is likely to lead them to a much greater awareness of each other’s specific roles, and perhaps a better-utilisation of services. The same participant (as above) in FG 2 provides a story of work developed to support carers in crisis, whereby HSC professionals’ knowledge and skills were shared effectively.

*“We’ve developed work which is funded by the ‘Better Care Fund’ ... 3 organisations working together and that way we can utilise each other’s areas of specific skill and service delivery to best effect to support a carer who is potentially reaching crisis point. Involves clarity of [each other’s] role and clear and agreed processes: whose doing what, how we share information, how are decisions made? Enabled to work together by putting in a joint proposal.” (FG 2).*

It still seems that there might be some organisation barriers in place, as for the above story to work; it did involve work on a joint proposal. However, that appears a good start and the test of effectiveness of sharing knowledge and skills, will be if this leads to better HSC outcomes for service users.

### **6.1.3 Experience of co-production and story-telling**

The research team asked participants what they thought of the process of co-production with NHS England, along with the power of story-telling. Whilst this question was posed towards the end of the focus group discussions, and participants had some interesting insights to share, an evaluation of co-productive processes could be a whole additional research project by itself.

#### **6.1.3.1 Carers: Sharing and helping others**

One participant (carer) in FG 1 conveyed they had learned much as a parent, having a son receiving care. They wanted to be able to use story-telling as a way of sharing best practice with others. However, they illustrated that even though stories can be powerful, there are more complex issues to consider in making meaningful changes to services.

*“There’s a lot of learning that we’ve [as parents have] ... I’d love to share that if it can help other people ... or processes ... who is the right person? Patient participation groups, various forums ... and a lot of people that would listen, but unfortunately they haven’t got the powers to make that difference ... need people within NHS England who have that role or responsibility [to listen/take action] ... parents will talk about stories ... but when you analyse what is to learn from that there is nothing there ... other stories [you see] there is a clear failing here and here and they’re very clear, need addressing. Getting parents [like second group] ... to take things further ... we can’t just pose problems to people, you’ve got to pose some solutions as well... a lot of the stuff at the moment gets lost, not being said or done in the right arena.” (FG 1).*

To promote story-telling and foster the development of integrated care and support, it is vital to have appropriate forums or discussion groups that are focused and constructive. As the excerpt illustrated above, there is the risk for discussion groups to descend into an opportunity for a range of complaints, where there may be little in the way of learning and consequently little constructive action to integrate care and support appropriately. The patient and carer voice should be heard, but for this to lead to tangible and

constructive change within the HSC system, commissioners and patient experience leads have to facilitate these groups effectively and be transparent regarding the impact the patient and carer voice will really have. In FG 1, another participant (commissioner) agreed and provided an example regarding the community mental health services and patient/carer involvement with the HSC Trust.

*“Focus groups; CAMHS ... we have very distressed parents [attend] focus groups but they had more solutions than we had in some ways, so collectively we put some of them together, but you have to let parents know, the public, the staff know; because the staff need to be involved also ... whole process, there’s no point having a talking shop is something doesn’t happen ... having joint solutions.” (FG 1).*

#### **6.1.3.2 Carers: Having a voice**

The carer’s voice is crucial to ensure the development of HSC services that are in line with recipients’ expectations and ensure that support is delivered at the point of need. However, the complexity of HSC means that there should be an on-going process whereby stories are shared between service users and the HSC organisations and staff. One participant in FG 2 highlights that stories should be collated and acted upon.

*“It’s invaluable that you collate from conversations, as opposed to questions that are just ‘yes’ or ‘no’ answers and a bit of detail behind it. It’s just making sure then that the right people are hearing that evidence and utilising it, they don’t just bury it somewhere.” (FG 2).*

There is the sense then that story-telling and co-production is very much an *active* process, rather than just a listening exercise or “talking shop” as one participant in FG 1 stated. One might expect then that the process itself – having an open dialogue between HSC professional and service user/carer – would not only be constructive to promote integrated care, but also be helpful for the psychosocial well-being of patients and carers.

#### **6.1.3.3 HSC professionals: Promotion of story-telling**

HSC professionals were in favour of story-telling, but highlighted that this is not a particularly new concept within HSC.

*“We use story-telling within the organisation anyway and from a learning and sharing [perspective]. This [FG/co-production with NHS England] has been slightly different, which is good. I’m open to anything new to take back to the organisation. Story-telling needs to be out there far more within the wider [healthcare] economy ... within the media far more than it is now ... [story-telling] is not a new concept. Patient story-telling has been around for absolute years but it just seems to dip and hide and then reappear again ... it needs to stay.” (FG 1).*

It seems that the patient and carer experience has, for a long time, been an important part of the process of HSC, but that the concept or the way it is understood by HSC professionals has changed overtime, possibly eroding the value and utility of the practice. Another participant (commissioner) in FG 1 highlighted that stories are not always depicting positive care, and can be highly critical, but that HSC professionals and commissioners need to account for and act on this also.

*“You need brave leadership that will accept stories that are sometimes very critical of the organisation because you don’t improve or change unless people are honest and it’s the providers that need to hear the stories.” (FG 1).*

#### 6.1.3.4 HSC professionals: Evidence-base

Progress has already been made with the participant (above) from FG 1 drawing attention to a number of HSC professionals that had received training to collect patient stories to be used as an evidence base at board level, alongside other, more objective, data.

*“We’ve just tailor-made a course (this new manual); just trained, often do joint stuff with staff and volunteers and service users, just trained 34 staff to be able to conduct patient stories, because we want them, not just at the boards every 2 months, we want them at the team meetings, the divisions, the events, we want them permeating ... the story today [with participant 1] was amazing – that’s what changes hearts and minds and cultures and policies ... good to complement ... observations of care, focus groups ... collectively ... coming out at number 1, there’s nothing more powerful than somebody telling a story.” (FG 1).*

In addition to HSC professionals welcoming story-telling as a method of learning and sharing practice, it also appears that story-telling could be utilised as an evidence-base alongside other more ‘harder’ sources of data; such as statistics and so on.

*“It would be good if [stories] could evidence both time and cost efficiency as well as better quality outcomes, if somehow we could find a way to demonstrate the best case scenarios and the best examples of integration ... better outcomes for both the professionals and service recipients.” (FG 2).*

The focus here is on the utility of stories based on whether they lead to measurable outcomes. Clearly, the way in which commissioners and providers facilitate opportunities for service users to share their stories will be crucial; being able to not only learn from the richness of individual cases, but also being able to take the distinctive elements of an individual case and make changes to the service that benefits others.

*“[Stories/co-production] something that is evidence-based has got to be the right way to go forward, definitely!” (FG 3).*

## 6.2 Narratives

A total of 26 narratives were received and subjected to qualitative analysis. Narratives were handled confidentially, and where specific details were provided by the narrator, which could have lead to a breach of confidentiality, the lead researcher (WM) edited the narrative before sending this for qualitative analysis by AB. The types of narratives are summarised in Table 2 below.

Table 2: *Types of narratives*

<b>Narrative Type</b>	<b>Number of Narratives</b>
Carers stories providing care	6
HSC professionals stories providing care to carer and cared-for (patient)	14
Letters of compliment	2
Letter of complaint	1
Family and Friends Test comments	2
Carer’s Workshop at a Service User and Carer Celebration day comments	1

Findings from the narratives are summarised under 4 main themes and a variety of subthemes (Table 3).

Table 3: *Narratives qualitative themes and subthemes*

<b>Themes</b>	<b>Subthemes</b>
Integration of services	Consistency between services Poor communication Problems of contracting care
Carer health and well-being	Stress Lacking a voice Identity
Carer support	Assessment Psychosocial support
Cared-for (patient) health and well-being	Complexity of care required

### 6.2.1 Integration of services

#### 6.2.1.1 Consistency between services

The experience of a parent/carer regarding the integration of services was rather mixed. Their son was receiving community mental health support, and whilst there were no stated problems with this, the carer had assurances that their son’s diagnosis of autism would lead to further support that did not transpire.

*“[Informed diagnosis] would open the door to help and support. However it didn’t. GP filled in forms and written letters for my son ... student social worker was of no help ... son attended college but staff did not understand his problems.”* (Nar. 1).

This excerpt illustrates the importance of HSC professionals knowing what sort of impact their work will have on the provision of other services. In this case, presumably the GP informing the carer that a diagnosis would make a difference in the availability of care, which never happened. Unfortunately, there appears evidence to suggest that even when a diagnosis is made, this might not lead to any further help and support, as evidenced in FG 3.

*“Story about somebody who was told there was no point having a diagnosis of dementia because it wouldn’t make any difference [to their care].”* (FG 3).

#### 6.2.1.2 Poor communication

Regardless of whether a diagnosis would lead to further support, with the hope that it would, the processes of communication could be far more person-centred that would allow patients and their carers to feel that they are at least being listened to.

*“Poor communication/interaction between specialists ... very little interest shown by the GP practice in my wife’s Alzheimer’s.”* (Nar. 5).

Perhaps HSC professionals need to realise that, even if they see patients on most days where a diagnosis of dementia is made, this will probably be the *first time* for the patient and their family/carers to hear of the diagnosis; even if they suspected this themselves. As such, the provision of a diagnosis, regardless of how common or routine it appears to HSC professionals’ needs to be treated as sensitively and compassionately as possible. The positive aspects of diagnosis appear to be if the diagnoses lead to an opening-up of support and access to a variety of integrated services for patient and family. When a diagnosis is made in isolation, as it appears to be conveyed by a participant in FG 3, as in a “medical model” context, this appears to close-down the range of carer support possibilities. Whilst good examples of care should be praised and shared, much learning can occur from these challenging examples.

*“[Carer] had seen her GP to example how she was struggling and felt she needed counselling ... GP rather dismissive of her and did not refer her for counselling.”* (Nar. 10).

The above excerpt illustrates that, for a carer looking after her son with autism, the experience was particularly stressful warranting counselling. It is reasonable to assume that many carers will display a high level of resilience, given they are exposed to the challenges and stresses of providing care every day for their loved ones. One might

expect then, that if a carer requests help and support, this will not be out of a lack of attempting to cope themselves, but because they really are in need of urgent help and support. HSC professionals have a responsibility to act on, sometimes the subtle, information carers convey that they require help. Again, when communication is effective, this can open up the possibility of access to additional help and support, and promote the integration of services where practice is shared and carers are supported holistically.

### 6.2.1.3 Problems of contracting care

The integration of services within today's HSC economy depends on effective contracting of care and support, often to private agencies outside of the NHS. Although many patients and carers may not take issue with care being contracted, problems can occur when the contracting of care is not done with the patient and carer's interests at the centre of planning and delivery of care. The excerpt below illustrates the story of a 94-year old lady receiving respite care at a care home, whilst her family carers were on holiday, only for her to sustain a fall and broken hip, with a subsequent admission to hospital, and after surgery, discharge back home. This patient was discharged back into the care of an integrated community team who then contracted to another care agency that was not her usual care. This caused a variety of problems where this patient's dignity suffered, and through physical and psychological deterioration she eventually died.

*“Mother discharged into the care of the newly formed Integrated Community Services (ICS) team ... contracted care to care agency ... not the team who had worked with her for several years previously ... mother didn't take to this new team at all ... should have been some flexibility ... [mother] would have done a lot better with her regular care team, continuity all-important with dementia [care].” (Nar. 6).*

Clearly, there are lessons to be learned regarding the processes of communication between the hospital discharge team and the community team. It seems only logical that this patient should have been discharged into the care of her existing care agency, whose carers knew of her needs, and there was already a good relationship between carers and the family and patient. This would have been especially pertinent given this patient's advanced age, mental health status, and physical health needs after hip surgery. In this narrative, the situation went from bad to worse, before improving again, as illustrated below.

*“After caring for [mother] for a month and with just one day's notice, the integrated community services team withdrew their cover and we were handed over to the Continuing Healthcare (CHC) team ... not able to find a care agency to provide cover at such short notice and we were left with nobody to look after my mother for the weekend ... I set up a camp bed and stay[ed] with her ... Hospice at Home charity had a volunteer [but] I felt*

*uneasy handing over to a complete stranger and leaving them together overnight. At this state the district nurses came to the rescue, they were fantastic ... [eventually] re-assigned to our original care agency.” (Nar. 6).*

There are clear failings of care in this instance, and this highlights that there needs to be far better service integration so that patients and their family carer(s) are not left without care and support when they need it the most. It is clear that this patient’s son was willing to do whatever it took to ensure continuity of care, in the face of care and support being withdrawn at such short notice, however they were still in desperate need of having care.

Unfortunately there does appear to be somewhat of a ‘postcode lottery’ when it comes to the provision of services and contracting of care, as illustrated below.

*“Definite imbalance of services and opportunities in different areas of the county and living in South Shropshire has meant far less being available from those living in Telford or the North ... my father is no less worthy as a human being.” (Nar. 15).*

From the family carer’s perspective, care and support should (rightly) not be bound by geography, but this appears an unfortunate reality, and highlights the need for more work to be done to address any instances where inequity exists.

## **6.2.2 Carer health and well-being**

### **6.2.2.1 Stress**

The excerpts above illustrate some of the challenges carers face regarding inconsistencies, poor communication, and taking issue regarding how care is contracted. It goes without saying that carers are going to be under sustained stress and at risk of ‘burnout’. Many transcripts had examples where HSC professionals either stated carers were stressed, or where carers expressed this themselves.

*“[Carer] described herself as being overwhelmed by the situation and appreciates an outside view.” (Nar. 4).*

Being overwhelmed is one of the fundamental aspects of psychological stress, where there is a perceived inability to be able to continue with one’s daily responsibilities and cope with challenges. Whilst it is worth stating that a certain level of psychological stress can lead to motivation to overcome a challenge, carers are typically under such sustained psychological stress that any motivational aspect of stress is eradicated, leaving the carer vulnerable to burnout and psychological breakdown. This indicates the above excerpt’s focus that the carer was seeking outside help and support, to ‘break free’ of the situation which was overwhelming for her, in this instance caring for her husband who had multiple sclerosis of many years, a recent diagnosis of Alzheimer’s disease, and acute hospital admission due to infection.

Stress is often compounded when carers' feel they have a lack of options to change their situation. In one narrative, this was especially the case when the carer stated they were an only child, and so when her father, in his mid-eighties, was diagnosed with Alzheimer's disease most of the responsibility to seek further guidance and support and provide care fell to her.

*"I had difficulty in getting [father] to the doctor, as he was in denial that there was anything wrong with him ... [father eventually] agreed to attend the memory clinic ... specialist doctor ... diagnosed Alzheimer's, offered medication, brain scan, promised monitoring follow up appointments with the mental health nurse and suggested I get power of attorney. Good advice, but there it ended, not further support was offered at this point, or any suggestion of where support and guidance could be sought, and it was some months before I heard from that service again. I am an only child so the responsibility was all mine." (Nar. 4).*

Fortunately this carer happened upon a display by the Alzheimer's Society and they made contact with them, which relieved a lot of stress and provided support. The stress relief manifested through a variety of factors, but being listened to and venting emotions appears crucial.

*"Straight away, I felt understood and supported and could ask silly questions and felt less alone ... advice on practical things (useful aids, strategies and finances) ... 'Singing for the Brain' sessions ... sharing my experience with other carers ... opportunity to share experiences and concerns and relief of bottled up emotions which are hard to share with family members as guilt and helplessness gets in the way." (Nar. 4).*

The chances are, this carer would have been able to discuss her stresses with the broader family, but the feelings of "guilt and helplessness" would preclude any realistic opportunity of stress relief and enhance coping. Having an perspective and provision of help and support outside of the immediate family appears to in some ways to 'depersonalise' the stress and anxiety and lead to a more objective and solution-focused way of working.

Another issue with narrative 4 was in the way even the specialist doctor's intervention led to no further support for the carer, even though at the time of diagnosis it appeared that it would. This harks back to narrative 1, highlighting the inconsistency between HSC services. This breakdown in integrated care and support is crucial as a learning tool, as there is evidence that carers might either be unaware of the support available or feel unable to access this. The responsibility/duty of care then falls to HSC professionals.

*"Carer was feeling physically and emotionally drained and was unaware of the support available to her." (Nar. 14).*

In the above narrative, the carer referred herself into the Carers Centre, on the advice on an Enablement Team, for further help and support but was unaware of how she could be helped. This person was caring for her grandfather who had Alzheimer's disease, and was supported through referral to specialised Alzheimer's disease support (Alzheimer's Society, Admiral Nurses, Young Carers groups).

#### 6.2.2.2 *Lacking a voice*

For carers, not having access to help and support, often outside of their immediate surrounding and situation, is stressful enough. However, even when help and support are offered, it is still crucial to ensure that carers are as involved with their loved one's care as much as realistically possible. Again, the issue appears to revert back to communication processes and the importance of carers feeling that they are being heard.

*"[Carer] offered ward staff information about her mother's care needs but felt she was not being heard ... very agitated and frustrated ... not involved in her mother's care ... repeating [information]." (Nar. 3).*

This must have been very frustrating for the carer as the person in question was her mother, whom she cared for approximately 10 years, before admission to hospital following a fall. Although one could argue that the hospital staff probably knew best regarding her mother's acute healthcare needs, having more involvement in her mother's care and support whilst she was in hospital would have resolved any stresses and conveyed to the carer that she was being listened to and had a powerful voice in her mother's care and support. This is critical given previous considerations around effective discharge planning and the integration of care and support when her mother would leave hospital. The interrelation between carer and patient health and well-being is self-evident and should be acknowledged by all HSC professionals across services.

*"The impact on [carer's] mental health was noticeable with her becoming increasingly upset, angry and feeling she would not be able to cope. This had a knock-on effect on her mother who also became upset." (Nar. 3).*

Maintaining carers' mental health is crucial, not only for their health and well-being, but also for the patient's and wider family circle health and well-being. When carers have a 'voice' in the care and support of their loved one's this seems to have a 'protective' effect on their health and well-being. HSC professionals need to be aware, however, of occasions when carers do not have the self-confidence or energy to seek help and support.

*"There is good support out there, but I have only accessed it, as I have been proactive and outgoing [what would happen if not?]." (Nar. 14).*

### 6.2.2.3 Identity

A possible consideration here might be laid to the notion of many carers not considering themselves as a 'carer'. Indeed, one participant during project group discussion (outside of the focus groups) remarked that the word, 'carer' is relatively new as a noun in common use, only since around the 1950s. One participant in FG 4 remarked that they did not really appreciate their identity as a carer.

*"I didn't really know I was a carer, I was just there on a dinner break going to Telford town centre many years ago. Someone from the Carers Centre ([I] must have looked like a carer!) waltzed up to me and said, 'excuse me, are you a carer?'. [I said], 'I think I might be', and that was my introduction to [being a carer] otherwise I'd have probably have carried on for another couple of years not really realising [I was a carer]."* (FG 4).

This interesting point led the researcher (SJS) to question whether the definition of a 'carer' needs to be broadened, to which participants felt much more clarity of the word and role was required, and how this would lead to extra support.

*"I think [the definition of a carer] needs to be clearer. Often when we're recruiting ... Carers Centre ... people assume we're paid carers, we're domiciliary care staff ... [respite] is nothing that we do ... I don't think the Care Act helped that at all, I'm not sure it was clear ... just purchased jackets and tee-shirts and on the back it states 'family carer', because if we're just carers, domiciliary care agencies, or people who want to be paid carers, come and visit our stand all the time."* (FG 4).

Here the focus is on the distinction between carers that are paid to care and on family carers, whose 'voice' is perhaps not as strong or as represented as others. Referring back to the narratives, the struggle to identify oneself as a 'family carer' can also be related to the sudden transitions imposed on them, when their loved one's become unwell.

*"[Carer] struggling to identify herself as a carer ... struggling to cope with the transition from being employed to full-time carer."* (Nar. 14).

The notion here of identity is a complex one, with a person's identity being intrinsically linked to multiple aspects of their life, such as their occupation for example.

## 6.2.3 Carer support

### 6.2.3.1 Assessment

One of the first ways in which carers receive support from outside agencies (HSC professionals) is through a formal assessment of needs, typically a Carers Assessment. This does not in any way deny that carers may have already received a wealth of care (for themselves and their loved one's) from

other family members or the friends, and so on, but that a formal assessment can facilitate additional help and support. There is good reason to assume that assessment of carers' needs can help to bolster their psychosocial well-being.

*"I was offered a Carers Assessment and counselling to be able to go to a pamper session about every 2 months." (Nar. 1).*

For a carer under a lot of pressure and stress to continue with their caring responsibilities and maintain their job, whilst looking after other family members, being listened to attentively and offered support sessions must be very appealing. An important point to reiterate here is that assessment does not become a generic paper exercise that is devoid of any person-centred focus.

*"Carers Assessment [revealed] husband's [carer] interests in photography ... but due to his carers role and finances this prevented him from affording a camera ... and time available during the week to pursue his interest." (Nar. 7).*

The stresses and strains on the relationship between carer and cared-for is crucial consideration for HSC professionals. In the narrative above, the cared-for was a woman who sustained a right-sided paralysis from a stroke and became unable to attend to her activities of daily living. This responsibility then fell to her husband who was then not able to find time to care for himself and pursue his own interests. After a Carers Assessment, and awarding of funding to support his photography hobby, this led to a significant improvement in his well-being and consequently his wife's well-being, along with a positive impact on their relationship more generally.

An important aspect of assessment is in making sure that information regarding the provision of help and support is up-to-date, reflecting the range of support services available to carers. In this instance, it is important that services are as integrated as much as possible, so that information (as previously outlined) is shared and carers are able to access help and support.

*"[Carer] would not have had up-to-date information regarding benefits or have the peace of mind of having her caring role documented by means of a Carers Assessment." (Nar. 9).*

#### **6.2.3.2 Psychosocial support**

Assessment by itself may not be sufficient in helping to provide carers with support they require. The importance here is in being able to conduct assessments in a proactive way that leads to actions and meaningful changes for carers. Assessment is a vital tool in enabling HSC professionals to provide evidence-based advice and support.

*"Support worker provided [carer] advice on how she might approach the issue [talking to the parents of the cared-for to ask for help] ... [cared-for] mother now helps one day a week with*

*dialysis machine and father now visiting and taking [cared-for] out ... freed-up time for [carer] to 'do her own thing'.* (Nar. 2).

The focus of the above narrative was on the complexity of care provision at home and the deleterious effects this has on the delicate family dynamics. In this instance, the parents of the person who was receiving care were struggling to come to terms with their son's health, having been bitten by a dog in 2013 and subsequently developed septicaemia resulting in kidney failure and seizures causing significant brain damage. This left him requiring renal dialysis at home every day, three times a day. Complicating matters even further was the fact the couple had two young children, one of which had autism. The immense strain placed on a family unit such as this is self-evident, and the provision of a Carers Assessment leading to help and support and building bridges between family members, was vital. This would not have been possible without the provision of advice by the Carers Support Service. In another narrative (below), the HSC professional were able to advise on how the carer could make their 'voice' heard in the provision of acute care to their husband, facilitating the process of effective discharge planning from hospital.

*"Able to advise [carer] on communication with the ward staff, and to insist her view [were] recorded on the patient's notes."* (Nar. 4).

Above all, what appears vital in the provision of psychosocial support for carers is in the way HSC professionals offer a 'friendly ear' for them to vent pent-up emotions and anxieties.

*"[Important for the carer] knowing there was someone who understood the way he felt and having someone to speak to. Someone who is not family ... [someone with] no agenda."* (Nar. 11).

## **6.2.4 Cared-for (patient) health and well-being**

### *6.2.4.1 Complexity of care required*

Documenting the various care and support offered to carers is vital, but so too is alluding to the complexity of care their loved ones' required in maintaining their activities of daily living and dignity. Understanding the complexity of care required, and of their situation in general, helps to contextualise the pressures and strains carers are placed under everyday. This facilitates understanding of the sort of support they require and how services need to be more integrated to enable this. The impact on patients' activities of daily living is apparent in the following narratives.

*"Had a stroke 2 years ago ... without any movement in the lower part of his body ... needs assistance with all aspects of daily living ... kidney failure ... [requires] dialysis at home three times daily."* (Nar. 2).

*“[94 years old] my mother was finding it difficult to cope with day-to-day challenges of living alone ... dementia developed ... could no longer follow a television programme ... increasingly isolated.” (Nar. 6).*

*“Cared-for has COPD [chronic obstructive pulmonary disease] ... mainly housebound. Struggles with mobility ... gets her down ... sleeps in a profiling bed.” (Nar. 11).*

*“[Carer’s] grandson has a learning disability and Crohn’s disease and requires one-to-one care.” (Nar. 12).*

## 7 Discussion

It is abundantly clear, from the findings of the focus groups and narratives of this action-learning programme, that collaborative working between carers, patients, and HSC professionals is vital to ensure the provision of effective care and support for carers. The NCICS (2013) highlighted that for too long the voice of (family/'informal') carers has not been heard by HSC professionals and other agencies tasked with providing help and support at the point of need. Going into an era when more people are living longer with long-term health conditions and requiring care and support at home (HM Government, 2008) the status quo has to change, and care and support needs to be far more 'integrated. Although there are challenges with determining the best way to integrate care and support, with complexity around the types of integration required (Goodwin et al., 2012), a starting point is in determining what is important to both carers and patients, in helping shape *their* health and social care needs.

This action-learning programme has highlighted a variety of considerations, discussed here on.

### 7.1 Toughest challenges for integrating carer support services

#### 7.1.1 Carers

It is clear that carers are faced with a variety of challenges in adjusting to their role as a carer. This can either be out of a lack of being able to cope physically and psychologically with the immense stresses and strains required of providing care 24 hours a day, 7 days a week; or it could be out of not having an opportunity to voice stresses, concerns, and vent emotions. Carers felt that the way information is shared between HSC professionals and other services could be much more efficient, person-centred, and timely. It was the experience of many carers that there was a degree of inconsistency of care and support between services, and even when they were assured that a diagnosis would lead to an opening of care and support, in reality this was often not fulfilled. Carers understood that part of the challenge for integrating support services was in the rather ad-hoc way carer is contracted. Although there was an appreciation that this is one of the many examples of the way in which the health and social care economy nowadays is structured, carers still considered themselves worthy of help and support regardless of where they live in England.

#### 7.1.2 HSC professionals

HSC professionals considered a variety of organisational barriers, such as the changes needed in the culture of the HSC workforce, along with changes in the way systems are administered bureaucratically, and the way funding is restricted. Concerning cultural change, it was evident from the focus groups that HSC professionals are continuing to work in 'silos'. The NHS Leadership Academy (2013) considers that team development interventions should aim to reduce potential for developing silo working by placing more focus on developing system thinking and a broader understanding of the HSC economy. Part of this process of system thinking is to help develop

opportunities to network with the broader HSC team and develop a common way of working whereby the ethical values and behaviours of all HSC professionals are aligned to the NHS Constitution (NHS Leadership Academy, 2013). Unfortunately, in the process of trying to achieve cultural change within the HSC workforce, there appears a parallel increase in the amount of bureaucracy in administering the change processes involved. There was an overt focus on the over-processing of information generally across focus groups and to some extent concerning the way some assessments were conducted to provide support to carers. Ultimately, assessment needs to remain person-centred and providing this helps to channel funding where it is required to meet the needs of carers and patients, then this would appear to be a way forward. HSC professionals placed considerable focus on the financial pressures of the system, and that even when they want to offer more detailed assessments or provide help and support for carers and patients, the limitations of the system and funding often rendered it not possible.

## 7.2 Examples of integrated changes

### 7.2.1 Carers

It was clear in both focus groups and narratives that when care and support was managed and delivered from an integrated perspective, this led to more comprehensive assessments being conducted and a greater range of care and support services being offered. This had clear impact regarding the cost-effectiveness of care and support services, along with assuring carers (and their family) that they were being listened to and a cohesive plan was being implemented. When care was integrated it also appeared to manifest as more adaptable to the needs of the patient and their carer and family. In this respect, co-production and integration appear to be interdependent concepts, and this further illustrates the utility of the current action-learning approach taken to evaluate carer support services. Integrated changes for carers means that their loved ones' do not only just receive the care and support they require, often from different agencies given the complexity of their HSC needs, but also that the carer receives a variety of help and support for their diverse needs. It was evident from both focus groups and narratives that co-production with carers helps to maintain carer psychosocial well-being and provides carers with an identity in the processes of providing 'informal' care and support for their loved ones'.

### 7.2.2 HSC professionals

HSC professionals considered some of the finest examples of integrated care concern the notion of discharge planning from hospital. This is one example where the co-location of HSC professionals and multi-agency working can prove to be highly effective. The outcomes of this can also be measured quite easily through the patient and carer experience and whether a patient's discharge from hospital goes smoothly. Part of this integrated working depends on HSC professionals developing meaningful and diverse networks with each other, having awareness of each other's knowledge and skills, feeling confident to draw upon the inter-professional team when required. Although there appeared some cultural challenges with this, when HSC

professionals continue to 'silo' work, the emphasis should continue to be on the patient and carer experience, and if the way HSC professionals are working do not appear to meet service user expectations, these systems of work need to change accordingly.

## 7.3 Experience of co-production and story-telling

### 7.3.1 Carers

Carers welcomed the opportunity to be participants in the process of sharing their experiences and helping others within the focus groups. The narratives also appeared to have been potentially very cathartic for carers, who were able to 'voice' their concerns in the hope that this would lead to changes in services. What is most apparent from carers' accounts of co-production and story-telling is the power of the person-centred approach, along with the impact of the utility of very powerful stories of when care has gone well and not so well. It is clear that HSC professionals and commissioners can learn much from carers being co-producers in their loved ones' care and support.

### 7.3.2 HSC professionals

HSC professionals commented that story-telling and, to some extent co-production, was not a particularly new concept within the HSC arena. The only caveat to this was in the way that story-telling and co-production have been prominent at different times and eras within HSC. HSC professionals emphasised that this method of working needs to be more embedded within the HSC economy and a 'normal'/everyday part of the HSC professionals work to provide care and support to carers and patients. Story-telling was considered to be a powerful evidence base which could be utilised alongside other, more objective ('hard') data, such as statistics.

### 7.3.3 Considerations for the development of a conceptual framework

#### 7.3.3.1 Carers

Challenges for taking the views of carers forward, in developing a conceptual framework for shaping integrated care and support, will be in respect of ensuring that the person remains at the centre of care and support and not reversion to a clinical/disease-focused approach. Valentijn, Schepman, Opheij, and Bruijnzeels (2013) highlight that the primary processes of care delivery to individual patients orientates to the 'micro' level (clinical) integration, and there is potential for clinical integration to be focused on the medical model (disease) rather than a person-focused approach. Valentijn et al. (2013) suggest that many of the tools and instruments of clinical integration are focused on disease-orientated medical interventions, which can be limited when considering the broader health and social care contexts of individual patients. The challenge in this respect will be in ensuring that HSC professionals empower patients and carers to be co-creators in their care and support (Valentijn et al., 2013).

### 7.3.3.2 HSC professionals

The integration between HSC professionals is referred to by Valentijn et al. (2013) as 'meso' level (professional) integration, implying the partnerships between HSC professionals within and between organisations and services. The important element of developing a conceptual framework here will be in ensuring that HSC professionals provide a "continuous, comprehensive, and coordinated continuum of care to a population" (Valentijn et al., 2013, p. 6). A conceptual framework would also have to consider how further integration between HSC professionals might lead to a blurring of professional roles and boundaries and challenges to the traditional hierarchy of the HSC system (Valentijn et al., 2013).

### 7.3.3.3 Additional considerations

The NHS Confederation (2008) reviewed the evidence surrounding integration and provided a conceptual framework relating to the notion of 'vertical integration'. This relates to the strategies that link different levels of care, for example, in respect of 'macro' level (system integration) – treating a patient's health condition – treatment is offered at different levels of specialisation, say from the general practitioner, to an associate specialist, followed by a consultant (Valentijn et al., 2013). This differs from 'horizontal integration', which relates to the strategies that link similar levels of care (Valentijn et al., 2013). For example, at the macro level of integration, a 'horizontal' focus will be indicative of the relationship between primary care and public health to improve healthcare in the community.

The development of a conceptual framework to enhance and sustain co-production between carers and HSC professionals will depend on ensuring that the 'micro', 'meso', and 'macro' levels of the service are integrated from both 'functional' and 'normative' perspectives. Valentijn et al. (2013) highlight that functional integration concerns the coordination of back-office and support functions, whilst normative integration concerns the extent to which the work mission, values, and philosophy of care are shared within the system. It is reasonable to infer that functional integration without normative integration may lead to better HSC efficiency but not necessarily increase the quality of care. Similarly, a focus on developing normative integration may result in care being more person-focused and holistic, but may also be a drain on finite HSC resources and unsustainable for the system. Clearly a balance has to be sought and the NHS Confederation (2008, pp. 10-11) offers some lessons for developing policy and guiding practice.

- Do not start by integrating organisations: This often may not lead to the improvements in care for patients and carers. This refers to 'horizontal' integration and can lead to significant problems, distracting from fundamental care. Starting at the level of clinical teams and exploring the patient's (and carer's) journey may be more worthwhile.
- Integrating fragmented HSC services may be beneficial but potentially unrealistic and too diverse a challenge: The time it takes to achieve integration across diverse services outweighs the benefits of attempting

to do so, in addition to maintaining the substantial learning curves in acquiring a new 'business' within HSC.

- Cultural differences between HSC should be considered: The ways in which HSC professionals work within primary and secondary care may be particularly strong. Integrating services may serve to strengthen perceived barriers to integrated working between HSC professionals.

At its heart, a conceptual framework to enhance and sustain co-production between carers and HSC professionals depends on the 'basics' of carers (along with patients and their families) and HSC professionals communicating effectively with each other. Patients and their carers and families need to know that the right care will be delivered, at the right time, in the right way by competent, courageous, compassionate, and committed [6Cs] (NHS England, 2012) HSC professionals. Furthermore, HSC professionals need to know that the appropriate structures are in place ('functional' integration), supported by a shared ethos of care and support ('normative' integration).

## 7.4 Limitations

As with all focus group discussions, the findings for analysis depend on the extent to which participants felt comfortable contributing to the group discussion. Whilst the majority of participants were able to contribute to the discussion, there may have been minority of participants who contributed less. This may be due in part to the fact that some of the stories participants shared were very powerful and 'guided' the direction of the focus group, with other participants reflecting and making sense of those stories in the context of their own position and experience.

For example, much of the discussion in focus group 1 (AJB) was focused around issues raised by participant 1. Whilst other participants did add their thoughts into the scenario participant 1 described regarding their son and his care, the power of participant 1's story was such that the group remained focused solely on the issues arising from this case. The researcher (AJB) was aware of needing to diversify, where possible, the focus of the group discussion, and made attempts to bring in varied considerations from other participants. However, the participants were keen on having participant 1's story at the centre of other considerations pertaining to the interview schedule.

## 7.5 Concluding remarks

The way in which collaborative working informs collaborative decision-making and joint planning for carers is relatively complex, with a variety of factors that facilitate and impede the development of integrated working. It is clear that having an open dialogue between carers and HSC professionals and commissioners is absolutely vital to ensure the development of services that are centred on the needs of patients, carers, and their family in accordance with the NHS Constitution (2013).

Collection of data on stakeholder practices with regards to carer support, as in the focus groups conducted and narratives collected in this action-learning programme, has proved essential to understand the complexity of the HSC

economy. Through triangulation of these data sources, it is apparent that for integrated care and support to be realised, there has to be on-going collaboration between carers and HSC professionals, with both groups learning from each other and putting into action meaningful and long-lasting changes to HSC.

## 7.6 Recommendations

The following recommendations have been considered and categorised in relation to the qualitative themes for carers (accounting for the views of the carer representatives) and HSC professionals.

### 7.6.1 Toughest challenges for integrating carer support services

#### 7.6.1.1 Carers

- Intermediate services may be referred to and enabled to facilitate care to patients when there is a significant transition in their care from one service to another, for example, from children's to adult services. This would not necessarily have to be an entirely separate service, which might otherwise compromise effective integration, but could be a team of specialised HSC professionals within the new service the patient is transitioning to.
- There could be more transparency in the sharing of information (providing it is relevant, timely, and maintains confidentiality) between HSC professionals and relevant services. This may enable carers not having to constantly repeat distressing information. Sufficient forums and opportunities could be provided for carers and carer representatives to share their stories of HSC to enable evaluation of services and drive HSC policy and strategy.
- Linked to the sharing of information, there could be a more specific focus on shaping care around the needs of the person (patient, carer, family), rather than expecting service users to 'fit' with the care that can only be provided in a restricted, linear way.

#### 7.6.1.2 HSC professionals

- An open debate/consultation could be considered between providers and commissioners of HSC services to overcome overt risk-averse and fearful ways of working. Risk-averse practices appear to be hindering the process of innovation and aligning HSC to be more in line with service users' expectations and needs.
- An evaluation of whether information gathered from service users is relevant and appropriate for the delivery of their care may be considered useful. There may be occasions HSC professionals collect a lot of information but may otherwise be restricted by this and not feel able within the limits of their professional role to follow-up on concerns outside of their assessment processes.
- An open debate/consultation as to what constitutes 'bureaucracy' or 'red tape' within HSC may be useful and help to clarify any ambiguities.

- Although there are continued financial pressures in being able to deliver HSC services, this should not preclude good communication between commissioners and providers on what can be offered to enable person-centred care. Furthermore, good communication should be upheld between HSC professionals and service users, to enable service users to be clear on what care and support they can receive.

## **7.6.2 Examples of integrated care**

### *7.6.2.1 Carers*

- HSC professionals and carers (along with carer representatives) should work collaboratively to co-produce (where possible) a care plan that enables the delivery of person-centred care but that may also result in cost effectiveness. Delivering care in innovative ways may not necessarily follow the normal pathway of care but may result in better outcomes for all concerned.
- The co-production of care and support is essential to uphold the processes of communication between HSC professionals and carers and ensure care is coordinated in accordance with the needs of the service user(s).

### *7.6.2.2 HSC professionals*

- HSC professionals could involve carers more in the discharge planning of their loved ones from hospital to home or elsewhere. Linked to recommendation 1 for challenges for carers (above), intermediary services could be referred to, enabling the process of the service user transitioning from one service to another. Carers should be at the centre of the discharge planning process along with the patient.
- Having local 'hubs' where there are teams of HSC professionals working alongside each other (co-location of work) may be helpful in developing and sustaining integration of services.
- Having regular opportunities for HSC professionals to meet with each other in a supportive, professional, and collaborative environment may facilitate the sharing of knowledge, skills, and experiences. This would also likely increase HSC professionals awareness of other services and help to enable collaborative working and co-produced solutions to challenges in integrated working.

## **7.6.3 Experience of co-production and story-telling**

### *7.6.3.1 Carers*

- Continued advertising of discussion groups between carers and HSC professionals should continue. This would continue to provide opportunities for carers to share their experiences with each other (for support) and with HSC professionals to influence decision-making in the procurement of services, enabling person-centred care and support.
- Consider ways of enabling co-creation (service users working with professionals to design, create and deliver services) to lead to co-production (service users taking over some of the work done by

practitioners). Forums and focus groups would enable carers to have a 'voice' in the creation and delivery of services.

#### 7.6.3.2 HSC professionals

- Consider a consultation period with HSC professionals to determine how they feel story-telling could be utilised more within HSC; not just through infrequent, formal group discussions and forums, but potentially in everyday practice. This would enable the service user 'voice' to be a constant element in the delivery and management of HSC.
- Consider ways of exploring further what 'integrated' care actually means to service users? Such an exercise would be potentially very useful in ensuring that integrated care aligns with service user expectations, and in ensuring that integrated care is not just another trend within HSC that will dissipate with the passing of time.
- Explore ways in which story-telling can be used to support the evidence-base of more objective ('hard') data sources.

#### 7.6.4 Integration of services

- Auditing the effectiveness of communication processes between HSC professionals, for example, between acute and community care may be helpful. Effective integration of services appears to depend, in part, on effective communication between HSC professionals.
- Auditing the effectiveness of whether contracted care meets person-centred needs will be important.
- Involving service users more in the way care is contracted to private agencies may help to ensure transparency and co-production is upheld.

#### 7.6.5 Carer health and well-being

- HSC professionals need to be aware of the diverse stresses and strains carers face in everyday life and work collaboratively to co-produce care that helps to improve and sustain the well-being of carers, patients, and the wider family.
- More advertising and promotion of carer help and support materials (for example, carer display boards, leaflets, and so on) will be essential in raising not only public awareness of the pressures carers' face, but may also capture awareness of carers themselves, to go and seek help and support.

#### 7.6.6 Carer support

- HSC professionals need to consult with each other as to how to adequately assess the needs of carers to enable proactive management and channel funding to enable person-centred care and support. A degree of standardisation (a 'check-list' as such) would likely be required to ensure efficiency, but HSC professionals would also likely require more time to conduct individualised assessments of needs, outside of a standardised measure.
- HSC professionals need to continue 'actively listening' to carers and effectively act on nuanced information carers provide.

### 7.6.7 Cared-for (patient) health and well-being

- As patients HSC needs become increasingly complex, and with more care being provided outside of acute hospital care settings, HSC professionals need to continue to ensure that care remains as integrated as possible. Effective communication between HSC professionals, across services, needs to be central to the way care is managed and delivered. This will ensure that care remains efficient whilst being person-centred.
- HSC professionals need to remain aware that provision of care is not just for the patient but also for their carers and family unit. HSC education programmes should continue to emphasise the 'biopsychosocial and spiritual' model in managing and delivering effective care and support.

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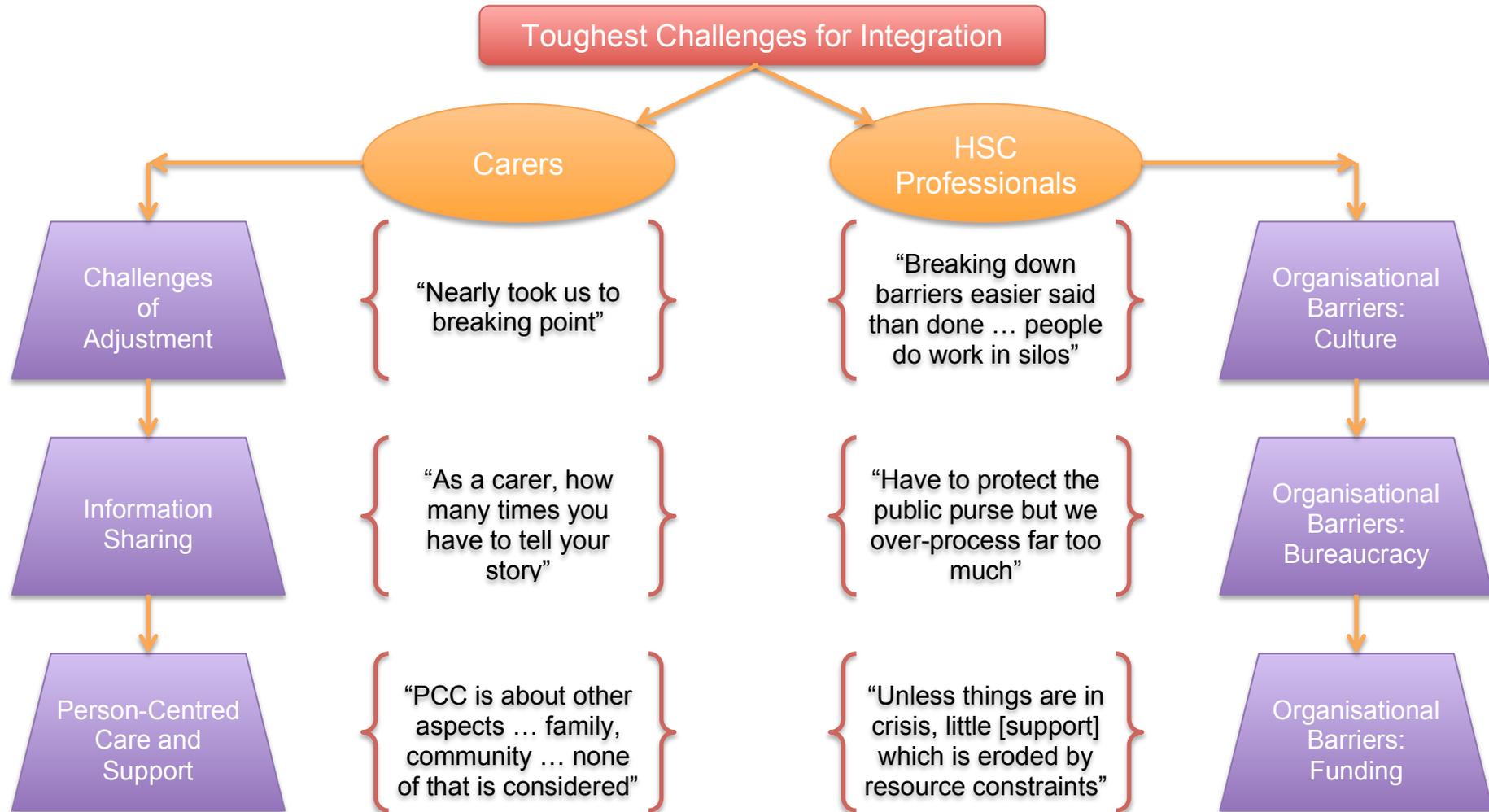
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## 9 Appendix

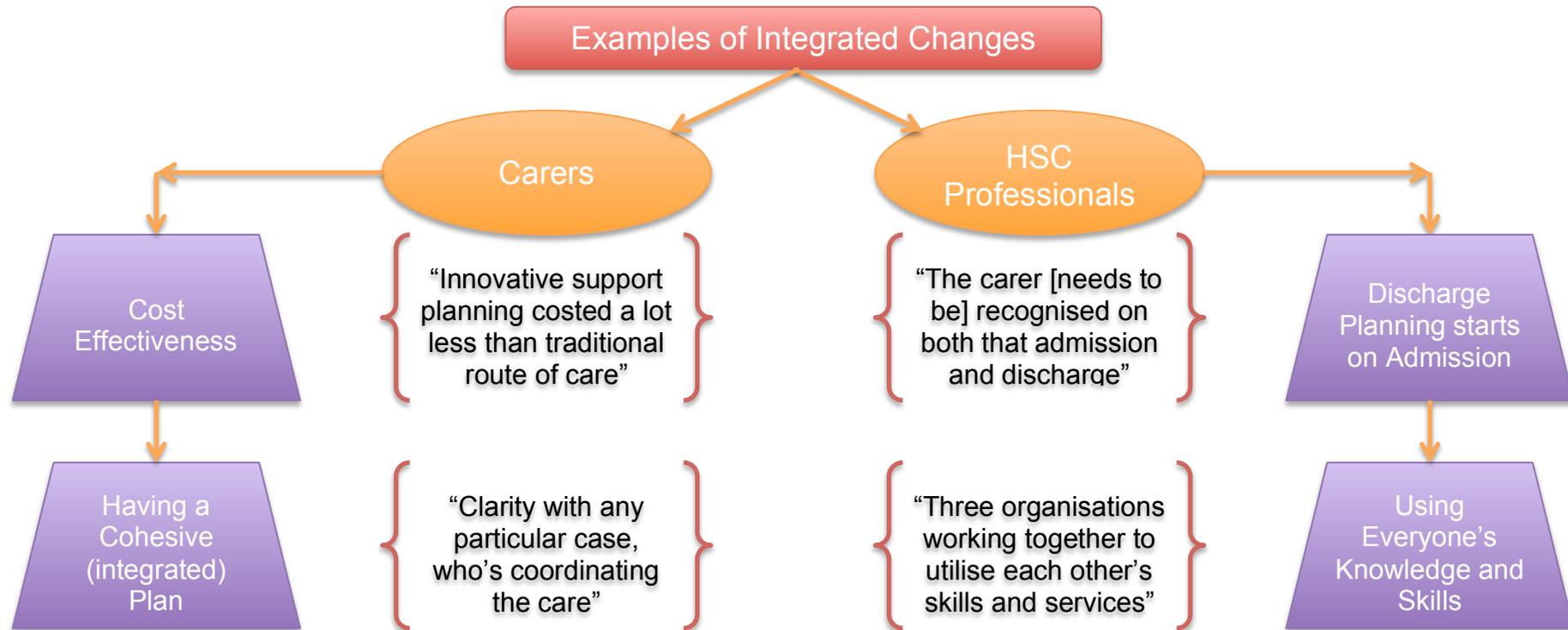
### 9.1 Appendix A: Focus group interview schedule (semi-structured)

- What are the toughest challenges you face with regards to integrating carer support services?
- What type of integrated changes would make the biggest difference to facilitating support for carers?
- What needs to go right for your organisation in order to integrate support and care services for carers?
- Learning from past experiences, what should your organisation avoid doing?
- What has worked well for you and your organisation when collaborating across health and social care?
- How have you found the model of engagement (co-production) with NHS England?
- What do you think of the power of 'story-telling'?

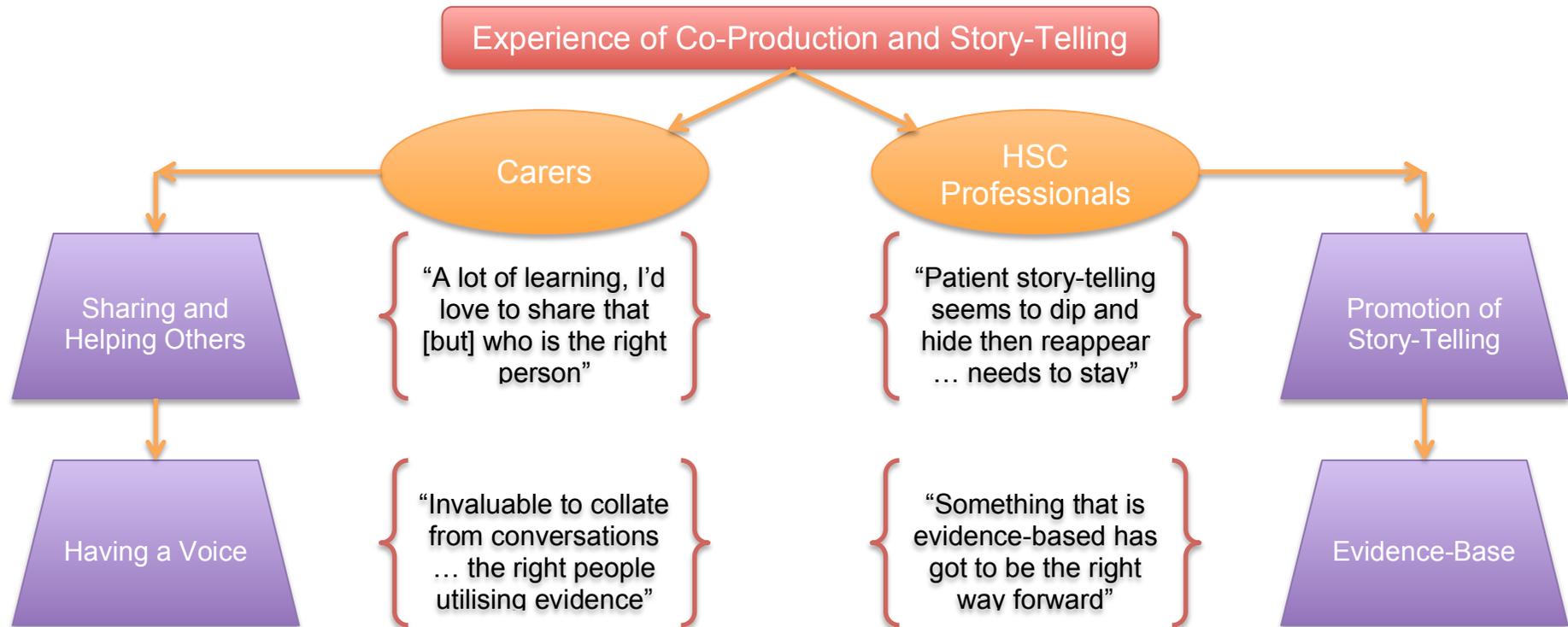
9.2 Appendix B(a): Summary of findings (focus groups 1)



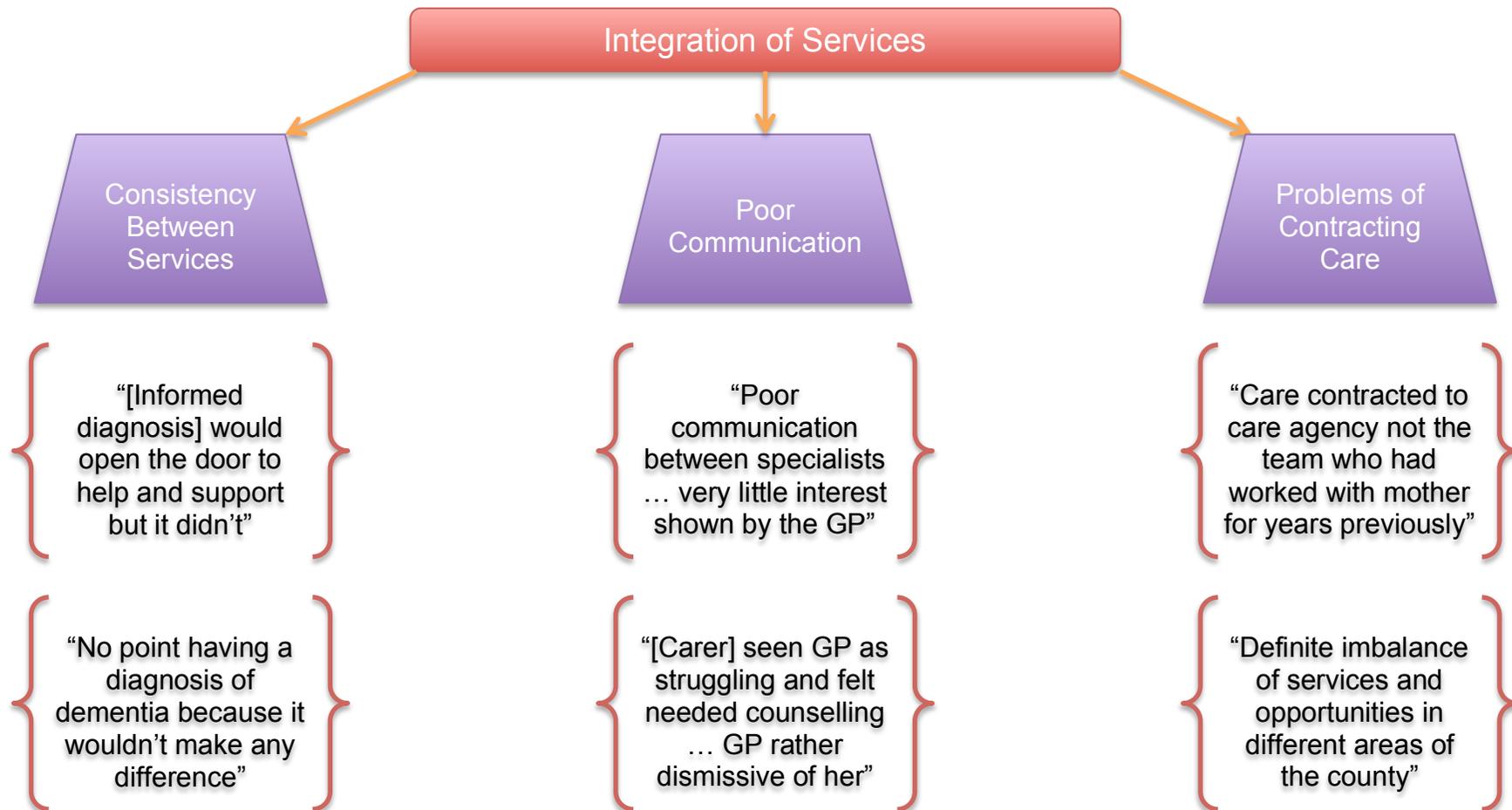
### 9.3 Appendix B(b): Summary of findings (focus groups 2)



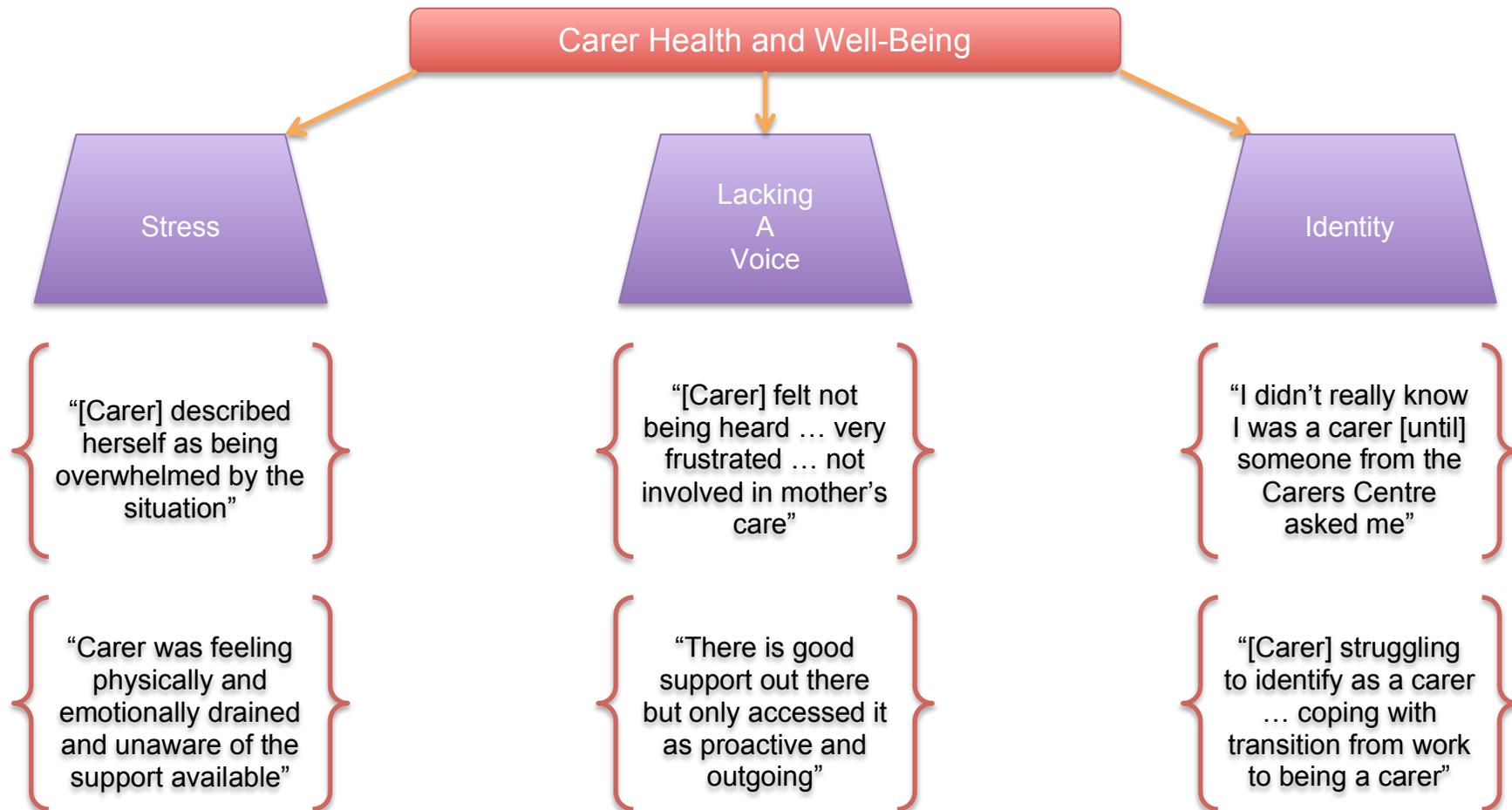
9.4 Appendix B(c): Summary of findings (focus groups 3)



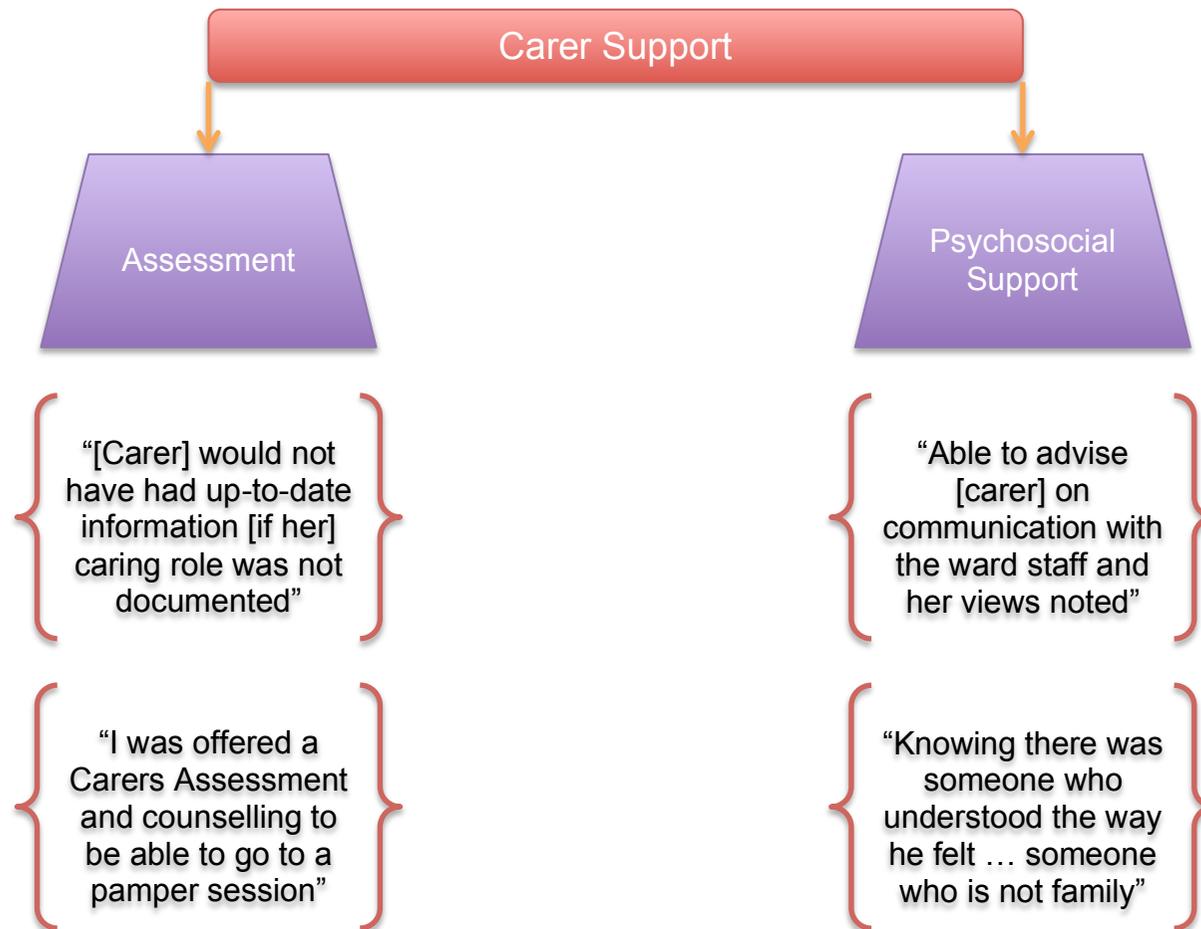
## 9.5 Appendix B(d): Summary of findings (narratives 1)



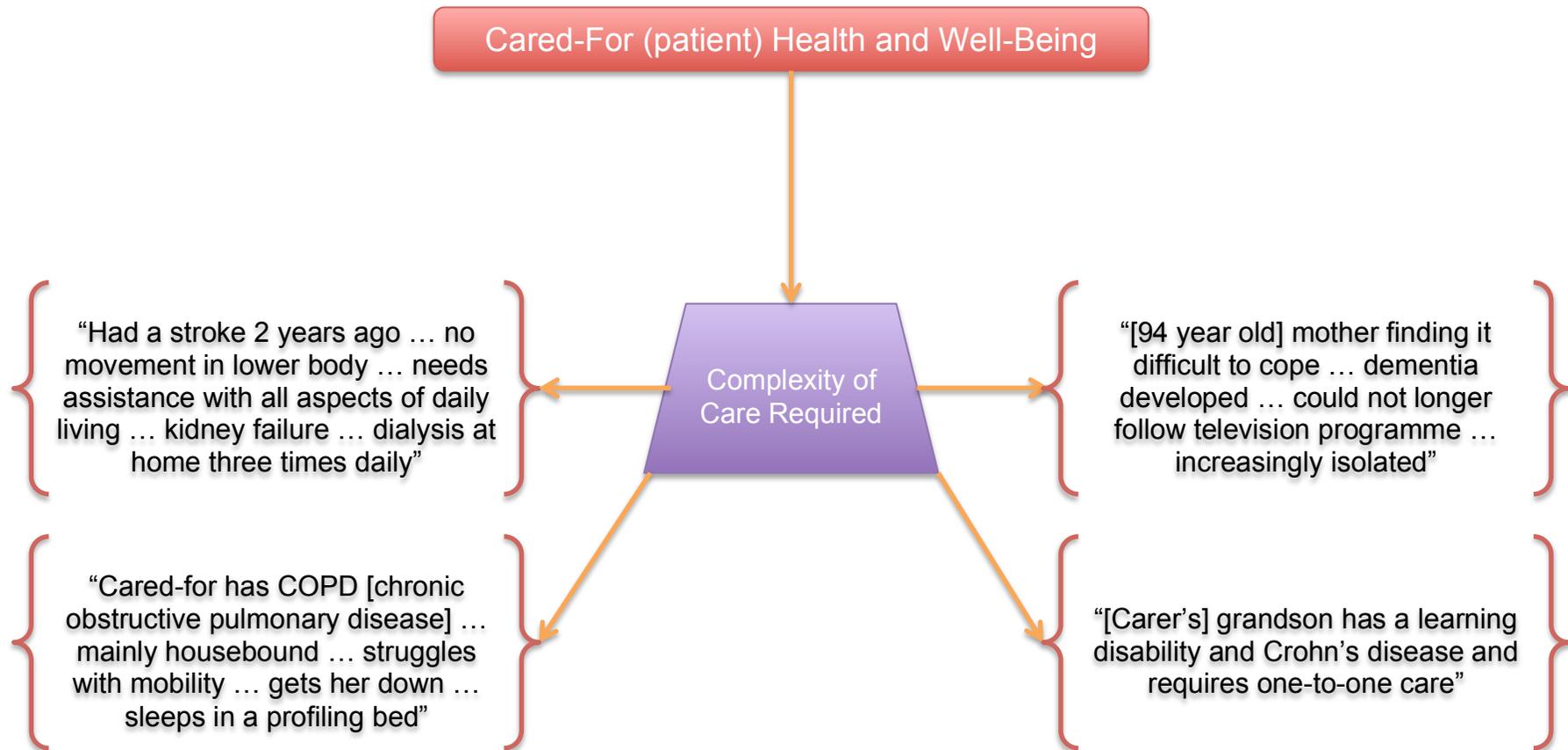
## 9.6 Appendix B(e): Summary of findings (narratives 2)



## 9.7 Appendix B(f): Summary of findings (narratives 3)



## 9.8 Appendix B(g): Summary of findings (narratives 4)



## 9.9 Appendix C: Overall Findings and Discussion Points

