

Health and Care Practitioner Insights: Understanding Information Sharing in Constellations of Care

Report on Amy's Page workshop series

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Foreword

From the outset, the focus of the Great North Care Record initiative was concerned with the support of multi-agency, front line care. When the Connected Health Cities programme was initiated, with its focus on the analytics of care data and the support of clinical research and innovation, the approach adopted in the North East Region was to attempt to combine these two sets of objectives into a single coherent architectural framework.

Previous national health IT programmes had been based on a centralised approach to providing information infrastructure to support care – the lack of success with this sort of approach lead us to consider the federated and distributed alternative which had been steadily gaining traction, particularly in Europe. This was based on the XDS Affinity Domain standards for the creation of local and regional, as well as national and international, Health Information Exchanges. The emerging success of the Lancashire Coast LPRES initiative was a source of further encouragement to explore these possibilities.

The core concept of the XDS Affinity is that of shared, third party middleware services deployed as a hub to a set of Agency Document Publication Servers and enterprise information systems. The federated system operates as a document and message exchange and signalling hub through which content is published, syndicated and consumed in the user sessions of “spoke” systems through the registration, notification, addressing and orchestration functions of the “hub”.

There has been a long history of research of this sort of approach to multi-agency service environments in the North of England, particularly concerning the relationship between the technical middleware, which supports the underlying mechanics and logistics of signalling, joining up and co-ordination, and the “human middleware” which we have observed operating in response to situations of complex health, socio-economic needs. This involves different carers taking initiative, within local encounters, to solve problems with their clients by communicating and coordinating with members of what we have termed “constellations of care”, that is to say, all the other members of the care community who have a relationship with the client/patient. Faced with the complexities, conflicts and uncertainties of long term conditions and the social determinants of health and well-being, “integration” from the perspective of the patient-client, can only be achieved dynamically by responsive and informed decision making and action at the point of need, rather than in combinations of pre-defined, single condition, care pathways and protocols which inevitable collide and conflict.

The result of this experience and analysis had been the development of an approach to professional user engagement and co-creative design called *Amy’s Page*. It involves facilitated discussions among representative members of constellations of care about needs to know and desires to inform in the context of care situations emerging from scenarios they develop together. The outcomes of these explorations are firstly, that the groups of

front line carers develop a deeper understanding of each other's practice and about new possibilities of care and secondly, sets of requirements on the contents, accessibility, presentation and consents, which must be supported by a messaging and communications infrastructure, are generated.

It is against this background that this workshop report is published with the intention of sharing both practitioners' insights and a tested engagement method. We hope both will be helpful to your future endeavours.

Professors Mike Martin & Rob Wilson

Northumbria University, May 2020.

1 Purpose of the document

This document summarises the approach, method and findings from twelve participatory design workshops – called *Amy's Page* – that took place with more than 150 health and care practitioners from across the North East and North Cumbria in England between 2017 and 2020 as part of the Great North Care Record programme.

The practitioner insights reported in this document are designed to inform programme decision-making. The *Amy's Page* approach is an iterative process – further sessions and further scenarios can be developed, refined and delivered to ensure that engagement and the *voice of the information user* is at the heart of programme delivery.

2 Background

Improved outcomes, safer care and good conversations rely on excellent communication and quality information to inform decision making by both service users and practitioners. The Great North Care Record (GNCR) aims to ensure the foundations for excellent, informed and appropriate information sharing to support individual care, planning and research in the North East and North Cumbria are in place.

Information sharing is an enabler in achieving the benefits espoused by integrated care models as multiple agencies, organisations and sectors seek to work more closely together to improve health and wellbeing for their benefit of their service users.

Understanding the information sharing insights, struggles and needs of practitioners and citizens is essential to achieve this aim, and the GNCR programme used the *Amy's Page* method to surface those insights - the voice of the information users - to better inform the wider architectural, technical, skills and privacy approaches.

There were other benefits too – the *Amy's Page* workshops enable people to get to know each other, identify partnership gaps, network and build connections providing a basis for a learning community to evolve.

3 Method

3.i About the Amy's Page approach

The *Amy's Page* method was originally created by Professors Rob Wilson and Mike Martin at Northumbria University. It was developed as part of a research project with speech and language therapists working with older people. They needed a way of facilitating an authentic conversation - which avoided the language barriers of “datasets”, “technical specifications” and “widget solutions” - between communities of practitioners about the information they would need to deliver a personalized care programme. *Amy's Page* workshops were designed so participants could safely share the realities of their necessarily complex work including their uncertainties and challenges as well as sharing ‘good news’ which allowed practice improvements.

The *Amy's Page* process begins with a small group co-creating a fictional service user scenario with the simple brief ‘who is our Amy?’ This Amy becomes the foundation for a subsequent workshop where practitioners are asked to map the different people, agencies and organizations that are involved in Amy’s ‘constellation of care’. Then, still with ‘our Amy’ in mind, to delve into their experiences as care professionals and identify, share and reflect on ‘what do I need to know’, ‘what do I need to write down’ and ‘what do I need to tell someone’.

The principles underpinning the method are:

- Insights are co-produced, and participants empowered to contribute
- Workshop will not define datasets or technical requirements – this is not ‘solving the problem’ but ensuring the voice of information users is available in the wider development process
- Workshops are not widget-design events – but the outputs may inform technical developments
- Better solutions emerge when the voice of the information user can be incorporated (‘ask the people closest to the work’) – we want to find out what practitioners think and feel about information sharing in specific contexts, e.g. End of Life, maternity or diabetes.
- Workshops offer a safe and trusted space to share uncertainties and practice

There are three stages:

Design: system leaders meet in advance of a workshop to collaboratively co-create a fictional *Amy* - *Who is the Amy that this service or product aims to serve?* - and plan how the session will operate.

Conduct the workshop(s): facilitate a group of practitioners to complete a series of tasks designed to surface their information sharing insights. Sessions may be audio recorded with participant consent.

Review and report: disseminate workshop outputs to project partners to synthesise, collate, analyse and inform social and technical developments.

3.ii Selection of contexts

Workshops were delivered in contexts where system leaders had approached the Connected Health Cities NENC or GNCR programmes. As part of this engagement activity, an offer was made to run an *Amy's Page* workshop either as an agenda item of an existing forum, or as a standalone especially invited session. Two of the contexts were CHC NENC care pathway exemplars and one of these included the *Amy's Page* element as part of its academic focus group series. It incorporated this dimension in its ethical application process.

3.iii The workshop tasks

The structure of the workshops leads participants through a series of tasks. These tasks are designed to enable peer networking and generate coproduced insights into the information sharing practice and requirements of their professional practice.

Task 1: Introductions

Participants were invited to introduce themselves, their roles and their interest in the topic. The size of the group dictated whether introductions were made in small groups or to the whole room. This enabled participants to make gain a sense of who is 'in the room' to build trust and enable networking.

Task 2: Validation of a fictional scenario

Fictional Amy scenarios (appendix two) were co-created by speciality experts in advance of each workshop answering the question, "*Who is the Amy that this service or product aims to serve?*" Participants were invited to review these fictional scenarios and assess how closely they represented the sorts of service users that they worked with.

Task 3i: The constellation of care

The third task was for participants to work individually to map the actors who play a part in this fictional Amy's 'constellation of care'. Participants were given a worksheet (see figure i) to note down potential points in Amy's care constellation:

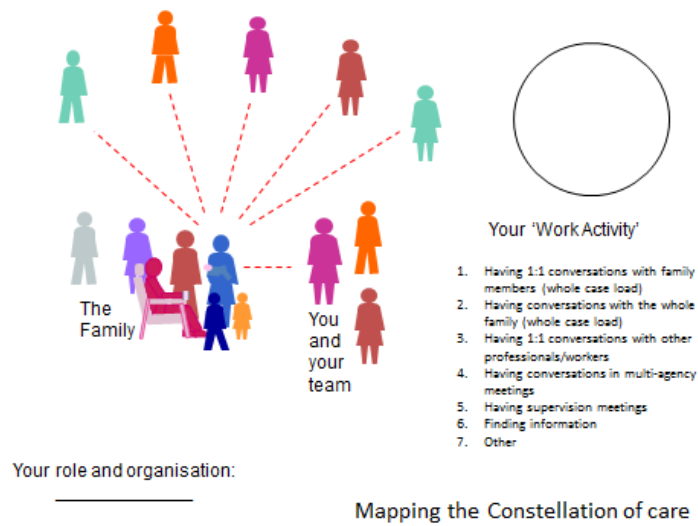


Figure i

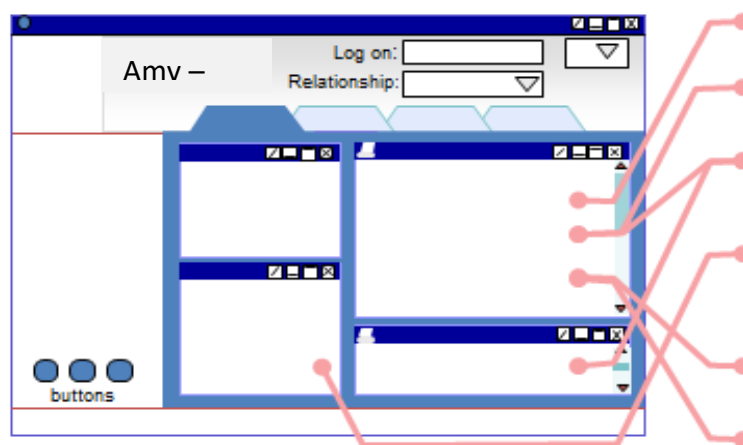
Task 3ii: Work activity and time allocations

On the same worksheet, working independently, participants were asked to estimate, by marking up a pie chart, how long in their working week they spent on 6 predefined and one 'open' task.

Task 4: Data requirements and sources - Amy's Page

Still with 'our Amy' and her constellation of care in mind, but this time working in small groups, participants were invited to design an information resource which would enable them, as practitioners, to have excellent care conversations with or about Amy. The context for those conversations was included in the fictional scenario, e.g. multidisciplinary case discussion or emergency department attendance. Participants were given a second worksheet (See Figure ii) to note their insights, and asked to collectively consider:

1. What information do you need to know
2. What information do you need to write down, and,
3. What information do you need to tell someone.



External sources of information offers and transactions.

Figure ii

Task 5: Reflective review

The final task was for participants to each complete a simple evaluation form inviting feedback on what they had enjoyed, liked or valued about the workshop, and how it could be improved.

4 Findings

We ran 12 *Amy's Page* workshops that brought more than 150 practitioners from health and social care, the voluntary sector and other settings together across 6 care contexts – frailty, end of life care, adult mental health services, perinatal mental health, vulnerable families, and the Healthy New Towns project.

4.i Participant roles

Over 150 people took part in the twelve workshops, drawn from more than 60 professional role types: participants were asked to identify their primary professional role or the 'hat' they were wearing for that workshop. Participants who didn't have a direct care role were invited to contribute from their service role, or act 'as if' they were a practitioner or other member of the community (n=2). A full list of participant roles is included in appendix 2.

4.ii Validity of the use case scenario

Fictional Amy scenarios (appendix three) were co-created by speciality experts in advance of each workshop answering the question, "*Who is the Amy that this service or product aims to serve?*"

Professionals attending workshops broadly agreed that they recognised this fictional *Amy* as typical of the sort of patient or client they work with daily, except for one group who worked with people with specifically complex social needs. Suggestions to improve the scenarios included adding more family and financial information – these could be included in future scenario iterations.

4.iii The constellation of care

Participants worked individually to map the actors who play a part in their fictional *Amy's* 'constellation of care' and were invited to include NHS, local authority, other statutory services, voluntary enterprises, family, community, commercial and any other actors they wanted to make a note of. The task was to co-create a picture of who plays a part in *Amy's* wellness NOT who should have access to *Amy's* detailed personal health record, and the crucial, granular distinction of potentially contributing information or concerns about *Amy* ('publishing') was made distinct from accessing a fuller record.

Participants charted a complex map of care delivery: the sheer number of people and organisations (actors) involved, sometimes 100s for any one context, was remarkable. Practitioners recognised the need for information systems that safely, legally and ethically support complex, integrated care.

The actors noted by participants were clustered into two sets – a universal set that was common to all the scenarios and then a list of actors noted in two or fewer contexts that were more specific to a specialty or context. However, a limitation of this analysis arises from language and naming conventions for different roles and services so best efforts were made to draw similar-sounding ones together. Furthermore, this report doesn't distinguish

between context and the scenario because of the way data was collated and transcribed – an improvement to future workshops would be to ensure these aspects are more clearly noted in the delivery stage.

It's important to state again that participants were **not** making recommendations about which actors should have access to view the details of Amy's health record but have a role to play in her 'constellation of care'.

Twelve clusters of actors were reported as being common in Amy's constellation of care across 4 or more workshop contexts:

- GP and GP staff *including out of hours*
- Voluntary, community, charity and third sector organisations
- Family – immediate and extended
- Social care
- Friends, peers, neighbours
- Financial – DWP, Benefits support, financial advisor, Macmillan benefit advisors, Life insurance provider
- Pharmacy, pharmacists and community pharmacy delivery
- Housing, local authority and homeless charities
- Neighbourhood and place: visitors to house incl. cleaners, private carer, delivery driver, postie, taxi drivers, paper-shop staff, environmental services e.g. bin lorry teams
- Police and community police
- CAMHS, NHS Talking Therapies, CPN/CMH teams
- Information and advice services

A full list of the clusters is included as appendix 3.

4.iv Work activity and time allocations

Practitioners reported spending a significant amount of their time finding information and in efforts to contact other actors in the care constellation by multiple 'analogue' means.

Therefore, the ability to signal who else is involved in someone's care – and how to contact them – could be beneficial for safety and efficiency. In one context, practitioners reported spending an average of 20% of their time finding information – a day a week of a full-time equivalent team member.

In one workshop, the range of participants and their contexts made this task work less well than it had done in other sessions. Informal comments made by that group, however, led us to surmise that similar issues – of time spent attempting to contact other practitioners involved in an individual's care or finding information – represent a not inconsiderable overhead in that context also.

4.v Data requirements and sources - Amy's Page

Like *Constellation of Care* task findings, the type and sources of data that practitioners reported would contribute to 'a good conversation with or about Amy' fell into two main

clusters – a universal set that was common to all the scenarios and then a cluster of data requirements that was specific to a specialty or context.

The completed worksheet responses were transcribed after the workshop. A clustering process was applied, and the following nine common data themes emerged:

1. Demographics, including patient's support network details
2. Professionals involved, including contact information
3. Care planning and care plans
4. Current, future and past appointments
5. Diary of observations
6. Medical history, letters and documents
7. Primary, secondary and tertiary care
8. Local authority information
9. Social situation and environment

A more detailed sample summary of the participants' insights regarding requirements is included as appendix 4.

4.vi Reflective review

Participants reported they valued the opportunity to reflect on joined-up care through the information sharing lens, and that rooting workshops in a fictional scenario made the process accessible and specifically helped overcome technical language barriers. Some suggested sending participants advance information to help prepare for the sorts of discussions that the workshop facilitated. In the first workshops, people from roles which did not include a direct care element commented that it was difficult to contribute – we then adjusted the invitation for them to consider the tasks from their non-clinical role perspective or to respond 'as if' they were a family member or GP.

5 Conclusions

The *Amy's Page* process was tested in the CHC NENC and GNCR programmes and shown to have value in surfacing practitioner insights which are relevant to the future shaping of integrated, person-centred care.

The workshop contributions are a reminder that people have complex lives and that care provision for many people comes from many actors and organisations alongside NHS and statutory services.

The rich map that practitioners charted illuminated that the challenge of information sharing is not single 'point to point' exchange but a many-to-many exchange, and the associated need for ethical, legal and safe information sharing where the citizens (people, patients, service users) are active actors in both governance and control.

This insight has implications for the planning, procurement, design, implementation and ongoing accountability for information sharing technologies and delivery, and for how each of these are supported by meaningful collaborations of stakeholders which represent the sorts of agencies and organisations noted in this process. As we look round the meeting rooms that do 'information sharing strategy work', are these key sectors represented and involved from the beginning? The idea of 'getting this right in health and then involve others' is challenged by the findings of these workshops which sets out a clear picture of the 'installed base'. However, the natural conclusion isn't a bigger record, but to work towards a bigger picture where constellations co-exist, supported by their own information exchange systems and can still talk to each other, supporting sharing and not sharing,

A key information requirement for efficiency and safety was that participants would value a way of knowing who else is involved in Amy's care and how to contact them for a conversation. A dynamic communications and contacts directory was deemed crucial for joining up care and improving outcomes, and saving time for patients and practitioners.

The importance of language emerged in every workshop too, that different terms mean different things to different groups. This also related to decision-making in complex care and the need to understand the impact and implications of care offers where different organisations and specialties meet, e.g. if I change XXX, what's the impact on YYY.

These findings and conclusions bring us right back to the ideas of a Learning Health System, and the valuable role that communities of practice and participatory design approaches like *Amy's Page* can have in bringing a Learning Health System to reality.

6 References and further information

www.greatnorthcarerecord.org.uk

www.connectedhealthcities.org

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Appendix 1: Workshops

Healthy New Towns	January 2018
End of Life	November 2017 to May 2018
Vulnerable families	October 2017 to May 2018
Perinatal Mental Health	January 2020
End of Life and Mental Health	January 2019
Frailty	October 2018
<i>(PLUS Adult Directors of Social Care)</i>	<i>May 2019, data not included in this report</i>

Appendix 2: Participant role types

"As if..." GP
"As if..." relative
Admin/Receptionist/PCN
Business Development Manager (BDM)
Care home provider
Care point manager
Carer
Case manager – HCT
Chief matron
Child mental health worker
Clinical manager/admission avoidance
Clinical trials (oncology)
Clinical Trials Officer
CMHT
Community advice and support practitioner
Coordinator
Coroner
Data manager/officer
Digital clinical champion
Digital health/palliative care company
Early help family work/family support workers
Education specialist
Employment and skills service/advisor
Friend (retired)/ friend of the family
GP
Health data science academic
Health visiting services
Hospice specialty doctor/physician
Hospital pharmacist for acute admission
Housing officer
IAPT
Independent (management) consultant
Liaison psychiatry
Local authority manager
Macmillan physio
Macmillan support service manager
Medical Consultant/community paediatric consultant/acute medicine consultant/geriatrician
Midwife
Modern Matron (older people's mental health)
Network Lead/Facilitator

Non clinical role
Not stated
Nurse (lead nurse/CNS palliative care)
OOH clinical service manager
Palliative care consultant
Palliative care team/community team/ manager
Patient activity reporting office
Pharmacist (lead clinical pharmacist)
Podiatrist
Police officer
Psychiatrist
Psychology
Receptionist
Registrar/SPR community palliative care/trainee
Resident Experience Care Specialist
RIACT senior practitioner
School nurse/school health
Social worker
Student nurse
Team Coordinator
Team Manager
Team manager – children’s centre play service
Voluntary sector (RMN)

Appendix 3: Sample fictional Amy personas and scenarios

Amy #1

Amy is 89 and has lived alone in Darlington since the death of her husband 10 years ago. She has family – including two sons- that live locally but they are all busy with their own teenage families and work lives and only manage to visit her once a fortnight. She lives in her own flat (which she owns), has a private cleaner who visits twice a week and makes a meal. Other than that, she is independent with her own personal and domestic activities of daily living although is finding this much harder. She has a pendant alarm.

She has a medical history of COPD, chronic kidney disease, diabetes, constipation and a history of falls. She has poor vision and reduced hearing.

She has been becoming increasingly frail over the last year and isn't getting out as much as she used to.

Amy is increasingly thinking about her options for housing as she recognises that she is no longer coping at home, she doesn't want to go into a care home but is unsure of what other options there are available to her. She is struggling to make meals for herself, has lost weight and spends increasing amounts of time sat in her chair as she lacks motivation to even make a drink. She attends a lunch club and has mentioned to one of the care co-ordinators that she is concerned that she is not managing at home.

There is no specific crisis but Amy's nephew (who is a community nurse) described her as a 'wobbler' to his cousin, Amy's son.

Amy #2

The Ords live in Blyth. The family are Karen, and her mum's partner, Ian Smith with Amy (13) whose Father (John) lives nearby. Karen and Ian have a 2-year-old child together. Amy's older brother also lives with them – he is called Connor, he is 17 and is taking drugs. Connor has recently been cautioned by the police for shoplifting. Connor goes to college but his attendance over the past 2 months has fluctuated.

John left the household four years ago, prior to which Amy witnessed her father perpetrating domestic violence towards Karen (physical and emotional abuse). John has taken to sporadically visiting the house to argue with Karen and Conner about money.

Ian's application for Personal Independence Payment has been declined. He has multiple aliases and is not currently in paid employment, having just finished a temporary job. Karen knows that Ian served an 18-month prison sentence approx. 10 years ago. Karen is being assessed for Universal Credit, money is tight, and she has to be selective about the food she buys for the family and this is supplemented by a local foodbank. Karen is having regular panic attacks about money.

Amy's attendance at school has become inconsistent, she has a supportive form tutor, Mr Dudley. Amy and her girlfriends spend time drinking and socialising in the park with her brother's (older) friends. She has an older boyfriend now (a friend of her brothers), who may be violent like Amy's father and her mum doesn't approve.

Amy regularly attends appointments with an early help practitioner. She has told the worker that her home life 'stresses her out', and that she argues a lot with Karen, 'who only cares about the baby' and is now 'always on at her about her boyfriend'. Amy has made reference to wanting to live with her Grandma, Vera, but she hasn't mentioned this to her Mum. She hasn't disclosed any further information except her Mum is angry and has threatened to kick her out. The early help practitioner thinks she has seen evidence of self-harm.

Amy's grandad died of Huntingdon's Disease and unknown to Amy and her gran, Amy's mum is in the process of being screened and is seeing a genetic counsellor via the same GP practice.

Following the death of her husband Vera has found it difficult to stay positive, some days she finds it hard to get out of bed. She has recently visited her GP to talk about this, who suggested she consider bereavement counselling.

Yesterday Amy has had her regular appointment with her early help practitioner having told her that she is depressed is going to "top mesen". The early help practitioner is very worried and has come to the Multi-agency team meeting and says the Team need to do something about this situation....

Amy #3

AMY is 40 years old and lives in her boyfriend's flat in West Tyneside. She moved to the North East for a job after graduating from university in 1997 with a fine art degree. Both Amy's parents died suddenly when she was six after which she lived with her grandmother in Sussex for five years but after she also died, she lived with her aunt until leaving for university. Amy is still close to her cousins although doesn't see much of them because of the distance and their caring responsibilities.

Amy says she started using drugs while at uni, but things got out of control in her early twenties. She joined a substance misuse programme and is a controlled methadone user, attending regular sessions at the specialist NHS Andrews Court centre. Amy has diagnoses too of depression and anxiety but doesn't have any prescribed medicine.

Neither Amy or her boyfriend have work currently, having both lost their jobs last year. Amy's boyfriend won't let her use the flat address for any correspondence because he is worried about the effect on his benefits and he doesn't want his address being associated with Amy's methadone programme.

Amy volunteers at a community arts project a few hours a week, and would like to do more but sometimes finds it difficult to attend the sessions because of low mood and being short of funds for the bus to get there. She walks her dog every day though but relies on contributions to feed him.

Amy rarely sees her GP. Three months ago, Amy told a friend she'd been having abdominal pain for quite a while, but it had got a lot worse. Her friend advised her to go to A&E. Following tests carried out there, was given a diagnosis of pancreatic cancer. She has completed three rounds of chemotherapy.

TODAY Amy is in A&E having been badly beaten up by her boyfriend.

Amy #4

AMY is 68 and lives alone in her own home in West Tyneside. She has two daughters – Tracey and Wendy - who both live locally.

Amy was diagnosed with lung cancer in October 2016 after being referred by her GP under the two week wait. Since her diagnosis Amy has lost her vision and is significantly restricted by this, unable to leave her home without accompaniment.

Amy was offered chemotherapy and had one cycle but stopped treatment due to side effects part way through the second cycle. Amy was then offered on going hospital follow up with the respiratory team though no further oncological treatment and was also referred to the community team, including Community Palliative Care, district nurses and Amy's GP. Tracey says the GP was a great help guiding the decision making process and talking through the difficult questions.

Amy's daughters are providing 24/7 care between them. A stair lift and environmental alarms have been installed, arranged by Amy's daughters with support and information from Community Palliative Care team.

Last week, Amy developed chest infection. The Community Palliative Care Nurse called on the Sunday and contacted the on-call GP, who called for an ambulance who then requested a 'big' ambulance. Amy was admitted to hospital: the hospital team didn't know about Amy's diagnoses, her blindness or yellow envelope. On discharge, Amy was sent home with two Zimmer walking frames and the family also collected a commode. The family were frustrated that staff didn't seem to know the system or process for loan kit and about who can do what.

TODAY, Amy is at home where DN records/care plan are kept (the family note that it is rarely viewed by other professionals). **Amy has a fall leading to crisis meeting at her house.**

Amy/Jackie #5

Jackie is 79 years old and lives with his wife in a downstairs flat in Saltgate, about 2 miles from Dunswell where he was born. Gordon, one of his two sons lives in West Tyneside, and the other Jimmy, in Waltonshire, 180 miles away. Gordon has a teenage son who has a severe mental illness and Jimmy has a bespoke cabinet making business and a school-age son.

Jackie had a building business and loved bricks and bricklaying until he stopped work a couple of years ago, due to knee pain. Although he formally retired at 68, he kept working 3 days a week because he loved it so much, being outdoors and chatting to all the folks passing by.

Jackie was diagnosed with hypertension at 65, T2 diabetes when he was 70 and severe osteoarthritis of the knees at 77. The long-term condition management was good with the osteoarthritis presenting the main problem due to reducing his mobility. Nevertheless, he went out most days with his wife and also paid a daily visit to the betting shop where he used to spend a hour or so having a 50p bet and enjoying the company of the other people. At age 79, after a fall and a few weeks physiotherapy at the day hospital Jackie started using a walking frame. A few short weeks after this his wife died.

Jackie is a war veteran after spending 3 years in Korea undertaking his national service duty. Being a member of the Korean veterans is very important to him, although he has to rely on taxis and his family to get to the monthly meeting now seeing as his car become too expensive an item.

Jackie can't leave the house alone; he relies on his family for running his home and meeting his personal and social needs. They spend between 9 and 13 hours a day with him, doing shifts.

TODAY – Jackie is attending a routine diabetes review appointment. Gordon, his son, contacted the GP last week worried that Jackie has had a couple of falls recently.

Amy #6

Amy is 29 years old and lives with her husband John, who is a paramedic in the coastal town of Whitehorse Bay. Amy studied early years education at university but left her job when she was 29 weeks pregnant as she intends to be a stay-at-home mum.

Amy gave birth to her and John's first baby, Jake, two and a half months ago.

It was lengthy labour and difficult delivery at West Tyneside hospital. Amy felt she did not have skin to skin contact and was finding breastfeeding difficult. Amy went home first then on to the maternity unit at West Tyneside hospital. Amy was finally able to feed Jake at the maternity unit and start to try and connect with him. Amy was seen by a range of midwives who all tried to help with feeding. During Amy's 24 hour stay, she was seen by five different midwives. They all offered differing and at times conflicting advice. Amy ended up breaking down in floods of tears that night and was told that this was 'to be expected'.

When Jake was 2 weeks old, Amy told the health visitor that she was feeling 'incredibly anxious' but was told that she would be fine. Amy told the breastfeeding co-ordinator that she was struggling to express but felt that the co-ordinator was only concerned that Amy continued breastfeeding. Amy was not asked how she was feeling.

By the time Jake was 6 weeks old, Amy was displaying out of character behaviour. Concerns were raised by friends and sister to Amy's health visitor and Johan was very worried about Amy.

Amy told the GP at her 6 weeks check that she was not feeling 'right' and cried through the appointment. The GP said it was the baby blues and to do something nice. A week later Amy walked into a GP surgery and begged the receptionist to take her baby away. A GP spoke to Amy and alerted Amy's health visitor. Amy was visited by the crisis team in her home. The crisis team deemed her 'not unwell enough' to be admitted and left.

Amy's behaviour deteriorated rapidly. Amy attempted to climb over the railings at West Tyneside train station to commit suicide. John stopped Amy, but Amy then ran towards the canal a bit further along the path. Another visit from the Crisis team with no action.

After Amy's behaviour become increasing agitated, she was taken to the out of hours GP by John. The GP recommended stopping breastfeeding and getting some rest.

Amy attempted to jump from a high level at a multi-story carpark. John and three friends managed to get Amy into the car and drove around until the crisis team arrived. The crisis team arranged a bed at the Mother and Baby unit for 2 days' time. Amy was sedated and her parents come to help John with Amy and baby Jake.

TODAY Amy was admitted to a specialist regional Mother and Baby PMH unit. The Specialist Community Perinatal Mental Health Team had not heard of Amy until this morning when she arrived in a very agitated and aggressive state.

Appendix 4: Constellation of Care actor list

Noted in all 6 contexts

- GP and GP staff (including out of hours)
- Voluntary, community, charity and third sector organisations

Noted in 5 out of 6 contexts

- Family – immediate and extended
- Social care

Noted in 4 out of 6 contexts

- Financial – DWP, Benefits support, financial advisor, Macmillan benefit advisors, Life insurance provider
- Friends, peers, neighbours
- Pharmacy, pharmacists and community pharmacy delivery
- Psychologist/MH team/clinical psychiatry / counselling / psychiatrist / IAPT team / CAMHS, NHS Talking Therapies, CPN/CMH teams, Streetwise / CYPs

Noted in 3 out of 6 contexts

- Housing, local authority and homeless charities
- Information and advice services
- Neighbourhood and place: visitors to house incl. cleaners, private carer, delivery driver, hairdresser and barber, postie, taxi drivers, paper-shop staff, environmental services e.g. bin lorry teams
- Police and community police

Noted in 1 or 2 out of 6 contexts

A&E staff incl. A&E consultant

Acute teams

Admin support

Advocate

Allied Health Professionals, Occupational therapy, Physio including

hospital/domiciliary/community resource team/environmental assessment. podiatrist

Ambulance service / NEAS / paramedics / Rapid response/ NHS 111

Amy / patient

Assessment worker – EHP

Behaviour support

Bereavement support worker/befriending service

Cancer services/oncology team/chemotherapy unit

Care teams / care plans

Carers/Home care, paid care agencies / sitting services

CCG

Chaplain/ Pastoral Service

Child protection team

Children's practitioners

Children's service manager

Chiropractor
Church or local activities + people connected to these
Citizens' Advice
Clinic coordinators
Clinical nurse specialist/hospital
Clinical photographer
Community and other specialist palliative care: Macmillan/other specialist palliative team /
community specialist palliative care team / Marie Curie / Marie Curie (overnight)/ Day
Hospice
Community care
Community centre reception
Community matron
Community nurses
Community paediatrician
Community worker (to support/monitor MH)
Complimentary therapy
Continuing Healthcare Team
Coroners
Crisis team
CSM Manager
CTT
Data (DCLG)
Dentist
Diabetes team inc outreach
Diagnostics team
Dieticians
District nursing team
Dog
Dom carer
DV support Freedom Programme
Early help practitioners / community services
Early years practitioners
Employer
Equipment services / loan equipment / stair lift company/ JELS
Family worker (to support daughters/contact with family)
FGC
Foodbank
FPs
HCA
Hearing clinic/audiology
Hospice: Hospice team/ team/day hospice/PV staff/hospice advice line
Hospital team from recent admission
Hospital team: medical ward/acute team / ward nurses/HCAs Care call staff / telecare /
Health Needs
Hospital team: Oncology team / acute oncology nurse in hospital / specialist nurse (lung
cancer) / chemo team/ discharge nurse
Hospital team: Respiratory team / respiratory consultant

IDVA
Integrated team
Intervention worker /team
Job Centre / Employment support
Key worker
Law: Power of attorney
Liaison nurses
Liaison psychiatry team
LifeLine
Locality meetings / locality team
Luncheon group/Lunch club
M&B Unit
MAT services, acute and community, MA, maternity care assistant
Matrix management arrangements
Meal making/Wiltshire Farm Food Delivery
Midwife, health visitor, EH worker, Breastfeeding support, secondary care service, BR coordinator
MSET
Multi-agency review team
NCT
Neighbourhood relations officer
NHS Screening
Nursery nurses
O2 provider + support team/delivery driver
OOH palliative care team / OOH nurses / Community OOH team
Optometrist/optician
Orchard / Mosaic
Other monitoring for LA/organisations
Outreach Services
Palliative care psychologists
Palliative care team (Drs/nurses)/ specialist nurse / specialist palliative care nurse /community palliative care nurse/ Consultants / palliative care consultants
Parent groups
Pathology team / lab
Patient transport
Perinatal team
Personalisation for bespoke services
Pets
Phlebotomist
Phlebotomy nurse
PHSN/Health Visitor
Physician
Platform (substance misuse service + drug and alcohol service)
Play service
PMH Team
PNIMH, Perinatal nurse
POONS team

Primary care
Probation
PWC (practitioner/senior practitioner)
Radiographer
Receptionists (not collecting rpt scripts)
Relate
Renal
Research teams
Researchers/research nurses /study professionals
RIACT/Falls team
RMNS
RNMH consultant
Safeguarding (adult, youth, GP, others)/child protection
Safer families
SARS team incl. EPS
School nurse / school health
Schools / colleges / training providers /education/teacher/form tutor / pastoral support /
attendance officer
Secondary care COPD/clinicians
Senior practitioner
Single Point of Access
Solicitor
Special Educational Needs
Specialist nurses (respiratory/diabetes/osteoporosis)
SPMH Team
Street triage
Student nurse
Sure Start / family centre
SV
SWs
Telecare technology/community care alarm services
Tertiary centres
Therapeutic services
University
Wardens, Care Home
Women's Refuge + other women for support
YJS
YOT
Young Women's Project
Youth associations and clubs / youth workers

Appendix 5: Sample Amy's Page information clusters

DEMOGRAPHICS – PATIENTS SUPPORT NETWORK DETAILS (CLOSE FRIENDS/ FAMILY/ NEIGHBOURS)	CARE PLAN	DETAILED MEDICAL HISTORY, LETTERS & DOCUMENTS
<ul style="list-style-type: none"> - Consent and level, ICE/NoK, LPA, relationships - Email, text, mobile no: - Consent preferences - Demographic data 	<ul style="list-style-type: none"> - Care package – commissioned/private funded 	<ul style="list-style-type: none"> - Medical history - Medical and drug history
CURRENT, PAST & FUTURE APPOINTMENTS	DIARY OF OBSERVATIONS	PRIMARY, SECONDARY, TERTIARY CARE DETAILS
<ul style="list-style-type: none"> - Consultants upcoming appointments - Appointment data 	<ul style="list-style-type: none"> - GP / Hospital history e.g. 999 calls, ambulance calls (tally in XXX period) 	<ul style="list-style-type: none"> - Secondary Care advisor - Other professionals / support receiving
ADVANCED CARE PLANNING	CURRENT, PAST & FUTURE APPOINTMENTS	LOCAL AUTHORITY
<ul style="list-style-type: none"> - Capacity/ DoLs - Life line info - LPA / MHS - Advocacy 	<ul style="list-style-type: none"> - Consultants upcoming appointments - appointment data 	<ul style="list-style-type: none"> - Social Care - DOS 111/ 999 - Social Care involvement - Links to resource in the community
SOCIAL SITUATION / ENVIRONMENT	PROFESSIONAL CONTACTS INVOLVED	
<ul style="list-style-type: none"> - Safe guarding concerns - Housing – owned – supported living - Care packages - Activity tracker link - Devices - Community Safeguarding alert - Community care alarm service - Access key safe - Volunteers - Devices – technology used - Links to resource in the community 	<ul style="list-style-type: none"> - Patients consultants' details - Lead GP & nurse - Community TAP team / DOS - OHH contact - Emergency Services used, ambulances, Lifeline other involvement 	

