SHARED PALLIATIVE CARE SUMMARY PROJECT

PROGRESS REPORT

Abstract

"If we're able to go to that patient group and have full access to everything, it means we can make a better, more informed decision about their care, which will mean that we get the care right more of the time. It's going to be massively beneficial overall." (Paramedic 2)

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Appendices

1. Purpose of the Report

This report forms the basis of the 'final' report for Connected Health Cities, delivered in June 2019. The original funding for the project was end on March 31st 2019, then extended to June 30th 2019 hence this document reflects that new milestone and achievements.

The aim is to inform and frame the learning from design and implementation phases of a digital health project, for the audience of Connecting Health Cities, current partner agencies, potential sponsors for the scaling up phase and relevant regional/national networks.

The report will be a compilation of all the key elements, presented as appendices, to enable readers to select their areas of specific interest.

2. Executive Summary (Progress report for SPCS)

The scale, scope and complexity of this SPCS Project has been very challenging, especially within the resources available. It has been and continues to be delivered through the tenacity and high levels of energy, flexibility and commitment of a core and wider team of partners.

The SPCS Project is well on its way to delivering the intended outputs of the project. The full impact will take longer to evaluate. However, the learning through the design and implementation phases are demonstrating a robust methodology that is gaining the confidence of partners and potential strategic sponsors. The outcome of these discussions will be the proof of the wider commitment, going forward.

The project has delivered:

- Robust criteria for defining an optimal EPaCCS system. These criteria were based on consensus from all regional stakeholder partners in the Palliative and End of Life Network. They focused on care around the patient, the systems involved and an agreed regional data set based on national datasets and requirements[1]
- A Shared Palliative Care Summary that is accessible to, viewed (and used) by practitioners to inform timely responses and care delivery (regardless of where the patient is)
- Insight into technical issues/risks arising during implementation across large and complex organisations and how to revise any issues with the Intra-operable system provider in a timely manner (appendix 2c)
- Insight into Information Governance and Clinical Safety Risk Issues for practical, clinical, intra-operable systems that are pushing the boundaries of current developments (appendix 6 Governance policies)
- Insight into (enhanced) relationship and trust between practitioners (quality/reliable use of system) e.g. voluntary initiatives to develop shared data and learning across agencies as project
- Identification, and adaptation of training needs, communications and quality issues relating to personal care recording according to the requirements of those organisations and working with their current models/methodologies. (Appendix 2c and 4, Amys page model, University evaluation material from planning phases, Key Learning Points in this report)
- Material/data to inform business model, policy and potential evaluation (appendix 3 Data profiles)
- A leadership/partnership team that can influence/inform future requirements (appendix 7)
- Construction of standardised data and performance indicators for regional use across the heath care systems
- Contribution to the development of regional digital pathways and developing regional governance structures
- Contribution to national EPaCCS FIHR standards
- Links to other national EPaCCS models and work
- We also have a model of formal evaluation that enhances credibility of the project with professionals and enhances their engagement in the process

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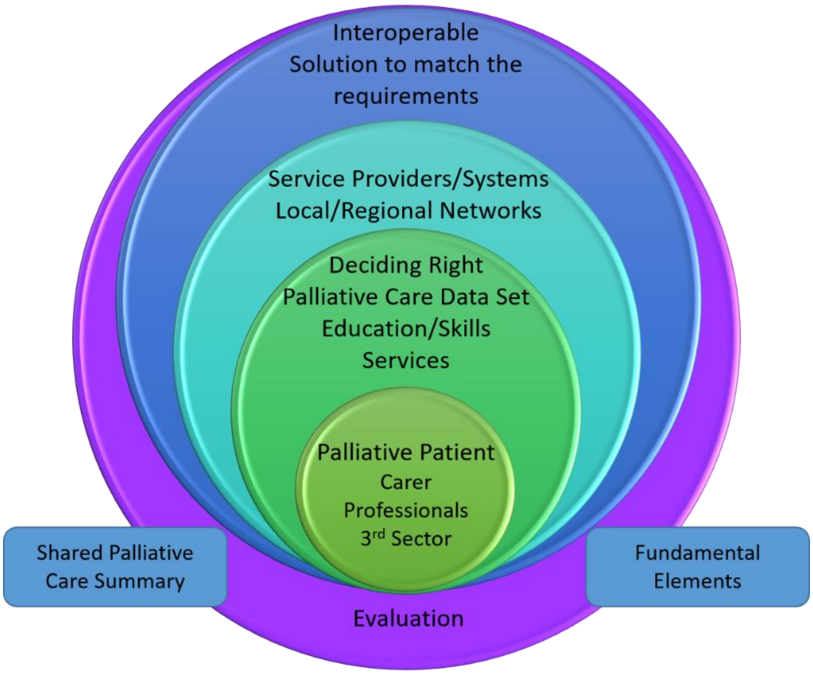
[1] Criteria & Evaluation of Palliative Care Coordination Systems. June 2017

Key Lessons for Sharing the Learning arising from the project

1. **Contractual arrangements:**
    a. Set up contracts before the project starts and understand the flow of the money to all parties
    b. Agree period & type of reporting, including financial balances
2. **Complexities within large secondary care organisations:**
    a. Secondary Care Hospitals are like a multi-agency organisation working under one umbrella
    b. Be prepared to work across all the dimensions of such a complex organisation
3. **Importance of strong leadership:**
    a. Ability to forge and maintain Partnership relationships
    b. Leaders (experts) that are willing to invest (personal energy), learn, be prepared for a journey
    c. Leadership traits to include influencing, working with autonomy
4. **Developing Governance arrangements in new relationships:**
    a. Do the right thing
    b. Ask questions, refine the questions, keep focused on outcome
    c. Hear the concerns and mitigate risk
5. **Respecting and using different ways of working and external factors that influence partners:**
    a. Keeping communications open (no place to hide)
    b. Engagement at all levels, use expertise and relationships available
    c. Build credibility/understanding
    d. Understand the impact on front line staff, those included and those not
    e. Keep the solution simple to read and use
6. **Patience, tenacity and follow through:**
    a. Build trust, at all levels
    b. To change behaviours at all levels
    c. Set standards/expectations
    d. Deliver

Diagram 1: A model of the construction of the project



3. Local Context

An electronic, interoperable, Shared Palliative Care Summary (SPCS) is being implemented in North Tyneside. This new way of sharing patient data will mean that health and social care professionals, involved in the delivery of end of life care, will be able to access key information about the patient, in real time.

Currently, the sharing of patient related data across multiple organisations involved in providing this care is challenging because of the different ways and systems in which data is collected, recorded and stored. (National issue.) [2]

The Palliative Care Plan project, funded by Connected Health Cities (June 2017 - June 30th 2019) has been working with key partners: Northumbria Trust, North Tyneside Clinical Commissioning Group, North East Ambulance Service, Northern Doctors Urgent Care, North Tyneside Community and Health Care Forum (Appendix 1).

We have engaged front line professionals from these agencies, throughout in the design, implementation and evaluation processes, generating an interest and anticipation for the benefits of the project.

We have also engaged with local people/patients, their representatives and patients impacted on by living with 'a long term or life limiting condition.'

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[2] Information: To Share Or Not To Share? The Information Governance Review April 2013

The project has been delayed in its implementation, largely due to several significant external factors over its 20 month lifespan. However, the product, people and systems in primary care (North Tyneside) NEAS and VOCARE have been operating since 'go live' on April 1st 2019 across North Tyneside. It is anticipated to have Northumbria Trust able to access the Summary in the very near future.

The contract with the product designer and provider, Black Pear, is for 12 months from the 'go live' date (April 2019).

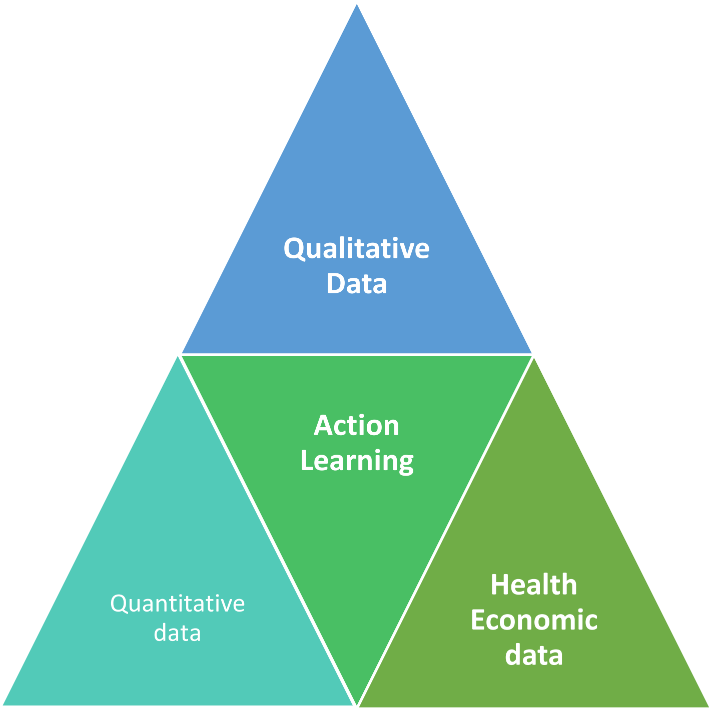
The project has been designed and run on a pilot basis, with a view to scaling up across the northern region and influencing the national Palliative Care environment and networks.

4. Evaluation of the Project

The original proposal included the full range of evaluation processes (see diagram 2 below). However, the formal economic analysis and full impact of the project has not been possible due to the operational delays referred to elsewhere in the report.

To date the project is able to demonstrate agreed baseline data, pre-implementation experiences and perspectives, and action learning (risk logs, lessons learnt). The planned stakeholder survey will be carried out before the end of June.

Diagram 2. Evaluation components



Quantitative data

- National core data - Audit/analysis (e.g. number of completed documents/missing data etc)
- Outcome data – (e.g. place of death; death in usual place of residence as per national documents etc)[3] including national and local outcome indicators. (Appendix 3. Connected Data Profiles)

Economic analysis

- Outcome data
- Training/education required, etc
- Professionals time, etc
- Computer solutions and maintenance of systems

Qualitative data

- Interviews with professionals and care users – academic rigour ensuring validity of intelligence
- Action learning approach to capture the project implementation process

5. The Project

Connected Health Cities

Connected Health Cities, part of the Great North Care Record Initiative, has sponsored the project over a 24 month period. Evaluation work commissioned by the Great North Care Record and carried out by Stephanie Steele provided an evaluation framework[4] for sponsored project. The logic model was applied to the SPCS and a diagram depicting the application to the SPCS project is included in appendix 1.

Current Status of the Project

A short-term extension to the implementation of the project (3 months) has been facilitated by additional funding from Connected Health Cities. The project will be hosted by North Tyneside CCG from April to June 30th to support this operational extension, to facilitate the roll out across all key agencies, as per the preparation to date. The formal evaluation element is not included in this provision.

Future Status of the Project

Funding and support was sought to facilitate:

- The final stages of implementation of the pilot (to include adult social care) to March 2020

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[3] National coding SC1580, National End of Life Care Intelligence Network Palliative care clinical data set 2018

[4] Logic Model. Stephanie Steele, December 2018

- Formal evaluation (based on the early evaluation carried out by our partners at Northumbria University) of the impact (patient, professional behavioural, service levels) of the project
- Identification of strategic sponsorship and expertise/leadership for scaling up and sustainability of the product design/function and further development of Information Governance for a sub or regional roll out across CCGs
- Connectivity with the regional clinical networks and support for sharing the lessons learnt across a multiagency/multi professional clinical networks
- Further development of Black Pear or other technical solution to meet system criteria

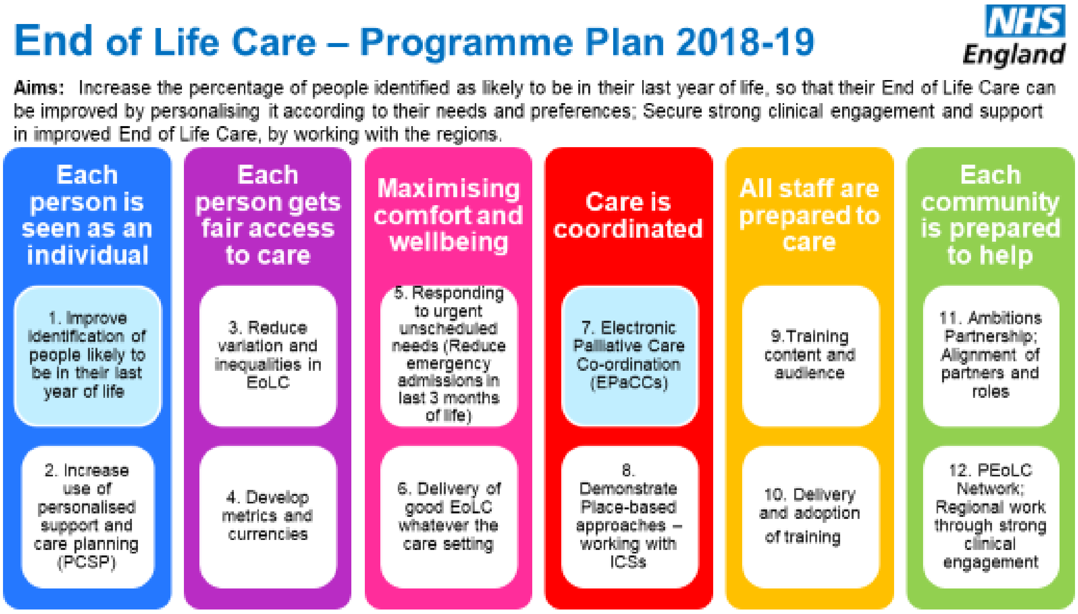
6. National Context

The SPCS project has informed developments and worked closely with national initiatives and amendments, such as the National Minimum Data Set[5], SNOWMED requirements National FIHR standards for EPaCCS, Great North Care Record[6], Academic Health & Science Network[7] and the MIG[8].

NHS England Programme

The Shared Palliative Care Summary Project addresses the NHS England national End of Life Programme 2018-19 **directly** in most of the key objectives (1,2,4,5,6,7,9,10,11,12). These have been aligned to the 'Ambitions for Palliative and End of Life Care' 2015-20.

It is anticipated that secondary benefits/impacts of the project will inform objectives 3 and 8 (see below, diagram 3).



End of Life Care – Programme Plan 2018-19

NHS England

Aims: Increase the percentage of people identified as likely to be in their last year of life, so that their End of Life Care can be improved by personalising it according to their needs and preferences; Secure strong clinical engagement and support in improved End of Life Care, by working with the regions.

Each person is seen as an individual	Each person gets fair access to care	Maximising comfort and wellbeing	Care is coordinated	All staff are prepared to care	Each community is prepared to help
1. Improve identification of people likely to be in their last year of life	3. Reduce variation and inequalities in EoLC	5. Responding to urgent unscheduled needs (Reduce emergency admissions in last 3 months of life)	7. Electronic Palliative Care Co-ordination (EPaCCs)	9.Training content and audience	11. Ambitions Partnership; Alignment of partners and roles
2. Increase use of personalised support and care planning (PCSP)	4. Develop metrics and currencies	6. Delivery of good EoLC whatever the care setting	8. Demonstrate Place-based approaches – working with ICSs	10. Delivery and adoption of training	12. PEoLC Network; Regional work through strong clinical engagement

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[5] John Willis, End of Life Care Interoperability Review NHS Digital, 2018. National Minimum Data Set and FHIR

[6] Project links to the Health Information Exchange developments in North East England

[7] AHSN working with Connected Health Cities (Newcastle upon Tyne, 2017- 2019)

[8] Medical Information Gateway, hosted by Northumbria Health Care Trust (NHS)

7. The ‘Connected’ Indicators & Data used in the SPCS project

To increase the numbers (%) of people who are identified appropriately, as within a year of the end of their lives, so that their care can be coordinated and delivered effectively and in a timely way that fits with their own preferences.

This in turn will (for patients registered on the palliative care register):

- Reduce the numbers of people (on palliative care register) who are transported to A&E Departments or admitted to hospital unnecessarily, (NEAS, A&E)
- Increase the numbers who die at home (stated preference)
- Reduce the number of repeat visits by out of hours services due to lack of up to date palliative care information (VOCARE)
- Increase the level of coordinated care in the place of the patients’ choice

In addition we will look to explore how to monitor:

- The impact on district nursing
- The impact on social care
- The impact for people living in nursing homes

The data from across partner agencies is being collated into single reports, on a sustainable basis, to explore the impact of the access to patient data, in a connected manner, to demonstrate the benefits for patients, impact on community and hospital services. See Appendix 3.

The Specific Deliverables from the project:

a. A proven interoperable system, across care agencies, that informs and promotes the development of integrated care for palliative patients that is transferable beyond N. Tyneside CCG and the NHS.

b. Collation and sharing of Data, intelligence and evaluation reports on an interagency level, to influence future professional practice, service/clinical pathway design and policy making for the wider health economy.

8. The Project So Far (diagram 4)

2017 – 2019 (Plan, Design and Test stages)

The project funded by Connected Health Cities, started in June 2017, originally to finish March 2019). This has now been extended to June 30th 2019.

The project has been significantly delayed (8 months) from its original proposed timelines, mainly due to various, significant, external factors, national, regional, local and technical. This project is addressing both complex and complicated issues and processes, see Appendix 2 (a,b,c). However, the project has:

- Engaged with many staff groups across the partner agencies and public focus groups in the design stages
- It has a workable and developing, interoperable product that was released to ‘go live’ in April 2019 across Primary Care (EMIS and TPP), NEAS, VOCARE
- A Training plan has been developed (i.e. learning/videos, presentations) with a delivery ‘team’ for implementation across primary care & secondary care, and e-learning for NEAS and VOCARE
- A communications package has also been developed for ‘awareness raising’ of staff users across VOCARE, Northumbria Health Care Trust and NEAS. These are bespoke for each agency/staff groups and support the roll out of the product across those agencies
- The project has a baseline of data profiles from partner agencies (consistent with other CCG reporting across the region) and interim evaluation reports that will inform the scale-ability and development of a business case for a regional/national roll out
- The learning from the project is being actively shared in order to contribute to the strategic interoperability agenda across the health, social and business communities
- Developed a working relationship with the IT provider to enhance understanding and promote greater interoperability going forward

However, the success of the design and implementation of the project is all about understanding and changing professional (behaviours) practice, challenging historical patterns of communication and building trust across the agencies, in order to gain effective engagement and the outcomes required for improving patient care. Hence the role of the qualitative evaluation stream of this project.

Managing change and embedding changes in practice in health care is notoriously challenging. We needed to address:

- the concerns/needs of key staff groups as well as organisations
- building trust with local patients/families
- including all care agencies in the system

The focus groups held by the project and the university evaluation team have produced great insight and learning for the project AND has built relationships and trust across the project.

The evidence gathered by the university evaluation team shows that we need to sometimes condense information to make it effective. Training and support needs to be available on a sustainable basis to enable robust professional practice to be maintained. This has been built into the implementation and proposed support for the coming 12 months.

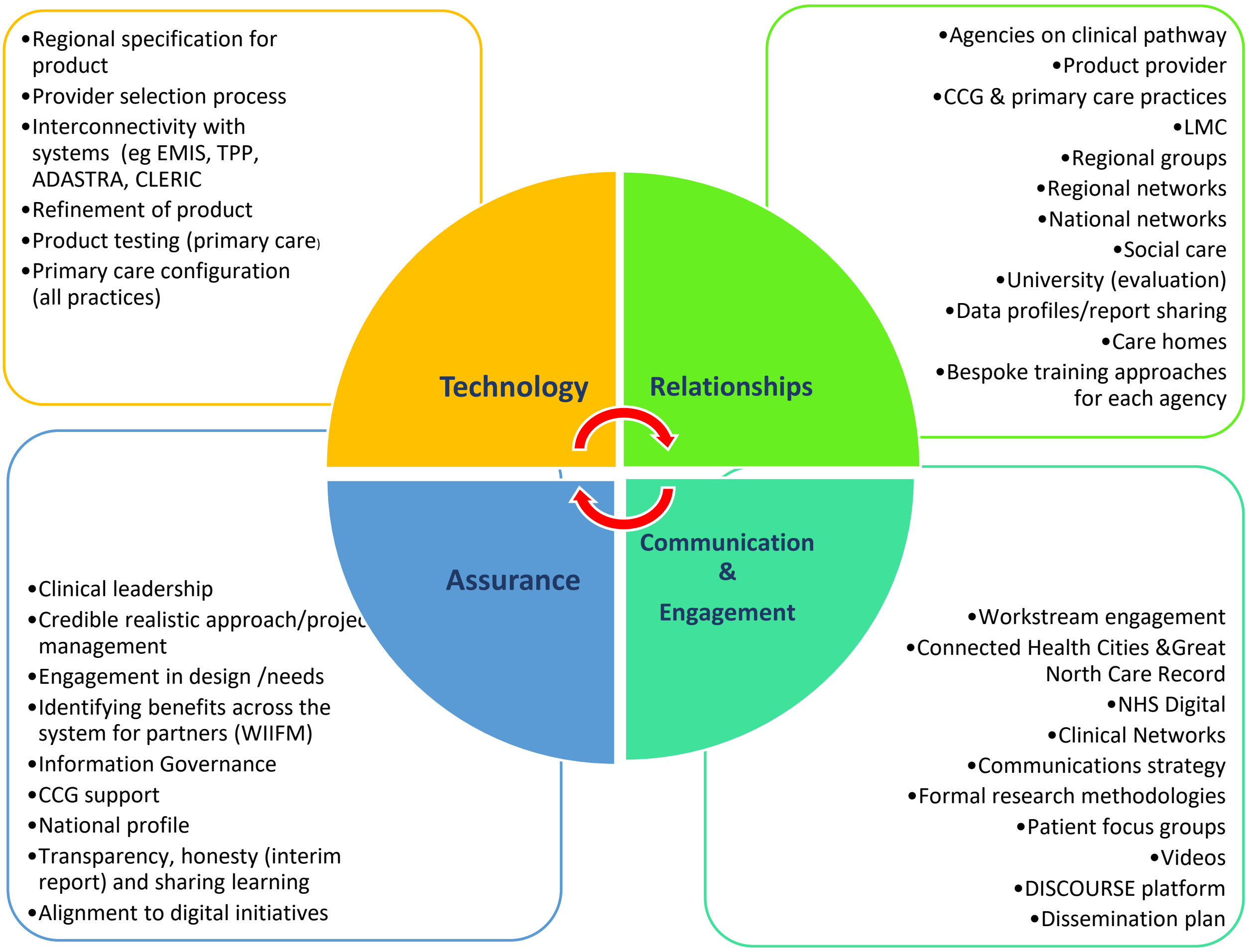
The Shared Palliative Care Summary is all about effective, real time communication.

I’ve done many projects before within health, and there’s a massive emphasis placed at the beginning of every project and they put it on. Then, afterwards, staff move away, because it’s not part of their project and we’re suddenly left with it. The system is changing and evolving, but there’s not always the infrastructure in place to support us to update it. I think that’s a real concern.’

Taken from transcript as part of University evaluation process. (2018).

9. Gaps & Caveats

The project is aware that there are also some willing partners that would like to and NEED to be involved in the project. The delays mentioned above have meant that adult social care, care homes, and hospices, in particular, have not been able to include in the solution to this project to date, although they have been consulted and engaged with throughout.



- Regional specification for product
- Provider selection process
- Interconnectivity with systems (eg EMIS, TPP, ADASTRA, CLERIC
- Refinement of product
- Product testing (primary care)
- Primary care configuration (all practices)

- Agencies on clinical pathway
- Product provider
- CCG & primary care practices
- LMC
- Regional groups
- Regional networks
- National networks
- Social care
- University (evaluation)
- Data profiles/report sharing
- Care homes
- Bespoke training approaches for each agency

- Clinical leadership
- Credible realistic approach/projec management
- Engagement in design /needs
- Identifying benefits across the system for partners (WIIFM)
- Information Governance
- CCG support
- National profile
- Transparency, honesty (interim report) and sharing learning
- Alignment to digital initiatives

- Workstream engagement
- Connected Health Cities &Great North Care Record
- NHS Digital
- Clinical Networks
- Communications strategy
- Formal research methodologies
- Patient focus groups
- Videos
- DISCOURSE platform
- Dissemination plan

Diagram 4 The Shared Palliative Care Summary Project

10. The Impact of the Project to date

1. Product refinement towards agreed specification

Whilst the product specification was drafted through regional consultation, various modifications have been required to fulfil the interoperability and governance requirements arising over the period of the project. Relationships with the provider have been developed to achieve these prior to 'go live' (1st April 2019). Examples include: mergeable form specific for NEAS, enhanced notification form for organisations, only 'push back' new codes not whole data set (staff do not want all info, just updates), imminent attachment of pdf documents e.g. EHCP.

2. Regional reporting for palliative care: CCG level

Through raising and sharing the profile of the project throughout, various CCGs across the north of England have established a reporting format, using the minimum data set (informed by the project) so that a regional approach is readily available for a scale up or wider roll out. Several CCGs are waiting for the implementation and impact of the project to be demonstrated to inform their own approach. Meanwhile the setting up of a regional EPaCCS network, developing project processes to support consistent regional approaches, consistent use of Read codes on SNOMED, with several CCG already accepted standardised approach and the use of RAIDR data – has steadily prepared this pilot project for wider implementation, once tested thoroughly.

3. Improved data collection and sharing by partner agencies

Discussions with partner agencies throughout has exposed the quality of data collection across the agencies. These discussions have led to improved data collection and voluntary data sharing, through the building of trust and identification of the potential benefits of the project. Examples such as NEAS End of Life data now being reporting regionally for each CCG, VOCARE (Out of Hours services), Care homes use of secondary care services.

4. Increased number of patients with Special Patient Notes (N. Tyneside) to NEAS

The improved awareness and profile of the project **alone** has led to a doubling of the number of patients with Special Patient Notes available in North Tyneside[9] (n = 237 to 576) with NEAS September 2017 – September 2018.

5. Collation of data reports for demonstration of impact

The collation of the reports into the agreed 'impact assessment reporting' with partner agencies is currently in progress. Presentation of the joint/shared issues was prepared for a Connected Health Cities event 2nd April 2019 (appendix 3).

6. Clarity of Information Governance Requirements

The project has some unique features. It is being developed at the front edge of the application of technology for patient centred solutions. It has established an information governance structure, with expertise from Connected Health Cities and Northumbria Health Care Trust especially. This IG structure has created a 'trusted environment' for partners to move forward, on a project basis (appendix 4).

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[9] K.Hall presentation 12th March 2019

7. Credibility and profile of the project to deliver

There is a full awareness of the challenges and active leadership support still required for the project, through the transparency and positive leadership style projected throughout the project lifetime. This has convinced the North Tyneside CCG to offer active management support for the implementation of the project (through the locality support officers and configuration of the PCs across the CCG) and the hosting of the project April 2019 onwards for Governance purposes.

8. Interim Reports (appendix 4a and b)

The Project has established ways of working that has created a transparent learning experience. Interim reports were produced in July 2018 to share the learning to date with Connected Health Cities and trusted sponsors associated with the project. This document forms the final report for Connected Health Cities, however future reports will be produced, according to the requirements of the sponsoring agent.

9. Project Management

We believe that the approaches[10] adopted by the project leadership team have been critical to the achievements (relationships, credibility, governance, deliverability) of the project gaining national interest and recognition, for example NHS Digital[11],[12] , NHSE.

11. Key Risks and Challenges

The risk and learning logs are attached in appendix 2.

However, table 1 below is a summary of those that were the most significant in shaping the project, challenging the project leads and agencies involved.

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[10] Project Management & Leadership for SPCS. Lynne Barr, Advancing Potential Un Limited

[11] End of Life Care Interoperability Review. NHS Digital. John Willis February 2018

[12] End of Life minimum Data Set. FIHR. October 2018

Key Risk Themes	Impact	Actions taken
Contractual: Understanding of company(ies) on detailed issues and holding to account.	Project has been able to help 'move ' the provider from a standard product to a bespoke product – testing the boundaries of what is possible. Improvements made during development period.	Need for a detailed specification. Retention/phased payment of funding. Handling the provider as a partner relationship (invite to meetings at the implementation stage)
Secondary care: Complex needs The range of needs, clinical specialisms and different use of systems in operation across secondary care creating a diversity and potential options. Strategic priorities and personnel changes.	Need to understand needs of different areas, possibilities of multiple solutions. Impasse. Lack of understanding/perceptions and poor communications/delays.	Focus on risks and benefits to organisation as a whole. Keep trying to' understand' with the long game in mind. Keep senior personnel engaged, up to date and show them progress/successes.
Information Governance: testing out new ground.	People raising the problems/risks but not the solutions. Challenges to the relationships within the project. Different understandings of the project requirements. Almost caused a complete hiatus in implementation. GDPR implementation 2018 led to concern, confusion and lack of clarity/guidance available for this project. Awareness of need for clinical safety officer role. (November 2018) New /revised governance arrangements will be required for roll out/scaling up.	Project management challenged and took responsibility to find out, sought external advice/support. Unlocked the level of '(mis) understandings.' Kept sharing the perceived understanding until engaged those who know. Experts engaged when they understood the 'real' situation. Project management communicated outcome of meetings. Confidence in project regained and implementation could go ahead. Seeking help = see sustainability Attended Connected Health Cities Event Summer 2018 (Rainton Meadows) Clinical Safety Officer nominated /provided by NHCT. Processes, templates and risks identified and communicated. Clinical hazards log completed with actions addressed on high risk issues. Modifications to project made. Clinical Safety Case Report in draft - preparing for sign off by stakeholder 's clinical safety officers.
External factors: significant factors beyond the control or influence of the project E.g. Wannacry	Partner agencies having internal technical problems and changes impacting on the project, CCG priority actions with primary care, staffing capacity and capability - numerous issues	Relationships and engagement with individuals to work through, over and around problems through the implementation phase. Developing videos and materials to suit each agency to enable understanding/training easily with different staff groups.

	Wannacry: loss of confidence in systems (patients and professionals). Closure of GP Practices, Delays in communications, time to complete actions to address shortcomings found.	Build credibility of project, address governance requirements, listen to concerns, transparency of communication and decision making.
Sustainability: delivery of the programme/capacity and scaling up	External delays causing implementation problems and capacity within the team to deliver the project. Funding has not covered the demands on the team or the range of skills initially identified. Skills for IG and strategic development across the region need to be enhanced for sustaining the programme. Standing Financial Instructions created a loss of formal evaluation process due to delays and inability to carry forward funding for later stages.	Personal commitment and tenacity of the project leads. Strong (clinical) leadership and in particular the continuation and enhancement of relationships (engagement) that are key to the implementation of the project. Flexibility and additional project management skills. (The lack of early clarity enabled flexibility and through mature communication drew on additional skill sets available.) Additional bids proposed but takes up more time/loss of best timing and continuity. Attendance at events, networks, raising the profile of the project, whilst essential, has not been included in the project bid. The project team as a whole works on the 'the right thing to do' rather than what has been identified/costed and paid for.
Staff concerns: Barriers to acceptance and changing practice	The formal pre project staff groups held by the university collected the concerns and issues for a range of staff. These are presented in a report. (appendix 5)	The concerns were noted and addressed through the implementation phase, training in each organisation, and in some instances the final design of the product. This has been time consuming, however has engaged the partner agencies further and sustainable training options have been created as a result.
Expectations:	Once the product was demonstrated and widely accepted as a good development, expectations of the product began to rise. The new ideas, whilst welcome, could not be accommodated in this pilot project. It was imperative to not lose the interest and momentum shown in these early stages.	The product has a 12 week initial 'live' period during which issues /concerns are being collected (protocol developed). Minor amendments related to the issues collected can be addressed at that point. other more significant issues can be included in a revised specification in the wider roll out plans.

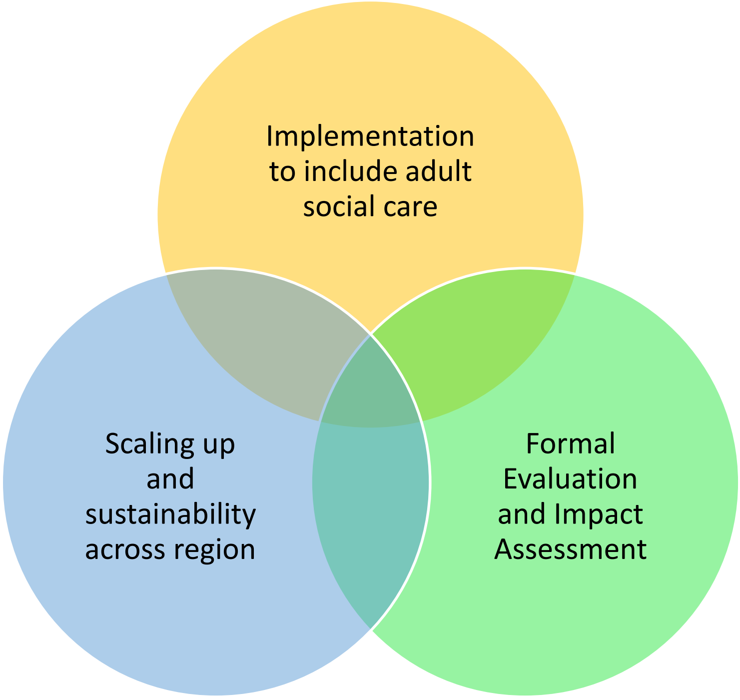
12. Next Steps

The project was originally funded until March 31st 2019. A further £20k has been received from Connected Health Cities to continue with the operational implementation of the project, to off-set the impact of the delays. This will last until June 30th 2019, with additional support from North Tyneside CCG. The CCG will host the project from April 1st 2019. This extension **excludes** the formal evaluation elements of the original proposal.

Three priorities have been identified for the next phase of the project from April 2019 (diagram 5)

a) Continued support for implementation and development (for period of contract with product provider)
b) Support for scaling up and integration with regional/national initiatives
c) Formal Evaluation and Producing evidence of impact

Diagram 5. Priorities for 2019-2020 SPCS project



SPCS Aims for 2019 - 2020

- To embed the initial stages of implementation across VOCARE, NEAS, primary care
- To address issues and implement with secondary care (NHCT-acute, A&E and community)
- To introduce the product to adult social care (Liquid Logic), care homes and hospices
- To support/ensure professionals can maintain engagement, overcome obstacles and modify/influence practice (their own and of others') as per staff engagement focus groups
- To review & communicate with public/patient forums in North Tyneside (appendix 4)
- To feedback liaise with Black Pear/make adjustments (initially April 2019, after 12 week from 'go live' and up to March 2020 (license/contract expires)
- To capture audit material/review to address issues arising/support (local) and Black Pear
- To informally evaluate the impact of the project on professional practice (re-run Amy's page approach). The formal university evaluation of the CHC funded project is still pending. External funding is being applied for from other sources to evaluate the health economic impact
- To gain credibility and inform relevant networks of progress
- To share the learning and risks/disseminate material across professional groups (regional/national)
- To lead guide the project towards a regional/scalable business proposition
- To support the university team to achieving funding for formal evaluation/impact of the project

13. Summary

The SPCS Project is well on its way to delivering the intended outputs of the project. The full impact for patients and on services will take longer to evaluate. However, the learning through the design and implementation phases are demonstrating a robust methodology that is gaining the confidence of partners and potential strategic sponsors. The outcome of these discussions will be the proof of the wider commitment, going forward.

The project has delivered:

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- Links to other national EPaCCS models and work
- We also have a model of formal evaluation that enhances credibility of the project with professionals and enhances their engagement in the process

14. Acknowledgements

The contributions of all our partners and their willingness to embark on this journey with the project is really appreciated. Many of whom have contributed additional focus and energy because of their commitment to ‘doing the right thing.’

Kathryn Hall	**Project and Clinical Lead**
Tiff Hodkinson	Black Pear
Michele Spencer	Community Health Forum
Lou Wilson	Connected Health Cities
Mark Walsh	Connected Health Cities
Henry Pearce	Data Design and Technology lead
Gareth Forbes	GP Durham & Darlington
Jonathan Harness	GP Gateshead
Fiona McDonald	Great North Care Record
Joe McDonald	Great North Care Record
Kathryn Common	Great North Care Record
Mark Westwood	Information Governance lead
John Willis	NHS Digital
Maureen Gordon	North East Ambulance Service
Paul Galloway	North East Ambulance Service
Paul Nicholson	North East Ambulance Service
Sarah Turnbull	North East Ambulance Service
Louise Watson	North East Clinical Networks End of Life Network
Marc Rice	North Tyneside CCG
Wally Charlton	North Tyneside CCG
Ruth Marshall	North Tyneside CCG /Care Homes
Georgia Douglas	North Tyneside Local Authority
Jane Wallace	Northumbria NHS Trust
Joanna Cox	Northumbria NHS Trust
Jonathan Walmsley	Northumbria NHS Trust
Lisa Sewell	Northumbria NHS Trust
Nick Lawson	Northumbria NHS Trust / Clinical Safety Officer
Richard Baksh	Northumbria NHS Trust
Wendy Murray	Northumbria NHS Trust
Hannah Gunn	Northumbria NHS Trust - Palliative care consultant
Tracey Best	Northumbria NHS Trust / GNCR
Katie Brittain	Northumbria University - Academic Evaluation lead
Angela Bate	Northumbria University
Becca Patterson	Northumbria University
Holly Standing	Northumbria University
Mark Lee	Palliative care consultant - Sunderland
Danielle Sweeney	Primary Care (Village Green Practice)

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Lynne Barr	Project Management Team Lead
Emma Raymond	VOCARE - Out of Hours
Julian Saul	VOCARE - Out of Hours
Juliet O'Neill	VOCARE - Out of Hours
Marc Herscovitz	VOCARE - Out of Hours
Maureen Taylor	VOCARE - Out of Hours
Sam Oldfield	VOCARE - Out of Hours

*Grey denotes chair or workstream lead

Appendix 1 Shared Palliative Care Summary: Logic Model (ref S. Steele)

Great North Care Record

Inputs

outputs

outcomes

impacts (End of Life patients)

- CHC staff
- clinical leadership & engagement
- university & researchers
- partners
- project management
- practice support team
- patient forums/engagement
- links to GNCR
- regional and national networks

- specification & interoperable product
- responses from early research activity (staff groups)
- action learning and interim report on planning & implementaiton
- governance arrangements across partners
- patient forums and engagement
- communications plan

- timely access to clinical data for EoL patients
- ability to view and edit info
- patient confidence in decision making
- professionals confidence in their decision making and that of others
- shared learning for implementation and roll out

- quality of care (% patients on palliative care register)
- care & deaths of EoL patients in place of their choice
- reduction in unnecesary revisits by OOH doctors
- reduction in unnecessary journeys (to A&E ,NEAS)
- reduction in deaths in hospital (over 8 days EoL)
- increased numbers of EoL patients dying at home
- costs of hospital admissions
- reduced A&E attendances (EoL patients)
- Lengths of hospital stay (EoL patients)

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