Communication and Continuity in Progressive, Life-Limiting Illness

A report by the Royal College of General Practitioners Northern Ireland

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Executive Summary

In 2011, the Royal College of General Practitioners Northern Ireland (RCGPNI) was commissioned by the Public Health Agency (PHA) to develop an ‘End of Life Care Passport’, as described in the Northern Ireland Palliative and End of Life Care Strategy. The communication tool which has emerged from this process differs greatly from that originally envisaged. This report describes the collaborative and iterative process by which the work was carried out. The development and design has involved those living with medical conditions, carers, patient advocate groups, and other interested parties alongside a range of health and social care professional representatives (see acknowledgements).

The evolution of the tool has been gradual, emerging from repeated and extensive discussion, piloting and reflection among stakeholders. It is a patient-held tool, which aims to facilitate the potentially complex network of key communication needed by many individuals living with progressive incurable illness and those who care for them. The communication tool aims to facilitate individuals to remain meaningfully engaged in community life and to anticipate and prevent crises, such as unwanted or inappropriate admission to hospital.

Training resources which have been developed to accompany the tool include a short film, a number of web based resources, guidance presentations and notes which will be available as ongoing web based resources. Students from the Department of Creative Technology at University of Ulster have also contributed design and artwork ideas to promote the use of the tool. Recommendations for further awareness raising and for public dissemination are also included.

While early evaluative work has been very positive, the time frame of the project has not been sufficient to allow for long term evaluation, and this is an important issue to address. It is likely that long term evaluation will result in modifications and adaptations to the tool, and we suggest that a facility, for on-going review and adaptation, needs to be built into the strategy for its dissemination and use.

Introduction

In September 2011, the RCGP Northern Ireland was commissioned by the Public Health Agency to develop a communication tool for those facing incurable, progressive illness. The “Patient Passport”, which was envisaged by the Palliative and End of Life Care Strategy for NI, was described in the strategy as a patient held tool which would facilitate communication and effective care and support.

In the course of consulting with patients, patient advocate groups, carers, and professional colleagues about the form which the ‘End of Life Care Passport’ might take, a number of key messages crystallised:

Firstly, affected individuals and carers reject the concept of an ‘End of Life Care Passport’, as being focussed on limitation rather than on possibility, and clearly stress their focus as being one of maximising wellbeing and living life as fully as possible. They emphasise that while a life journey with progressive illness may vary in duration from days to decades, the adaptive challenges associated with changing health begin in the earliest stages and continue until the end of life. Adaptation is a gradual and ongoing process of work, and communication is at the heart of this.
Secondly, the information needs of affected individuals and carers are very different to those of healthcare professionals and any communication tool needs to focus primarily on one of these perspectives. It also became clear that, while undoubtedly helpful, existing passport models were not designed to capture the potentially complex, multi-faceted and evolving nature of advanced illness and care.

Finally, the work has clarified the strong desire among many of those who live with progressive medical conditions to be viewed by their healthcare teams as ‘individuals-in-community’, rather than as ‘patients’; active members of social systems to which they make a rich contribution, and which help to sustain them, rather than simply as passive recipients of care.

The questions addressed in this work were:

- What is the purpose of the proposed tool?
- Who will use it and how will it be completed and updated?
- What is its content?
- What are the key factors in the design of the tool?

The tool which has emerged from the work focuses primarily on the information and coordination needs of those who are affected by progressive conditions and their carers. An allied tool, the electronic Key Information Summary, has been developed by NHS Scotland, who have offered it as a template for adaptation and usage in Northern Ireland. This will provide a vital addition in the form of a healthcare professional-centred information system, which conveys key clinical information from the GP record to interfaces such as Accident and Emergency and Out of Hours services, with patient consent. The RCGPNI believes that both tools have an important role to play in supporting those who live with progressive medical conditions, their carers and their healthcare teams to create and sustain a sense of coherence and clarity amidst the myriad of challenges of advanced illness.

Economic and Demographic Change

Global changes in demography, treatment and illness prevalence in recent years are resulting in much greater numbers of people living for longer periods with long term conditions. Healthcare strategies have shifted towards developing systems for supporting those with long term illness to lead meaningful, engaged lives in community and plan ahead to avoid unwanted crises. These strategies are also of key importance in meeting the economic challenge of sustaining publicly funded, equitable healthcare services. Communication systems are central to this task, and we hope that this work will be both timely and relevant in contributing to this process.

This report begins by focusing on evidence concerning the key communication challenges facing affected individuals, carers, and health and care professionals in the context of long term, progressive incurable illness. It will then describe the collaborative process by which the content of this communication tool has emerged, been evaluated and re-emerged. It will conclude by making recommendations for the implementation and daily usage of the tool and for its future embedding into health and care routines. Recommendations will also be made for further evaluation of the tool and for its on-going adaptation and contextual development.
Communication Challenges

Living with a Progressive Condition: Individual Perspectives

The experience of living with long term progressive illness involves fundamental challenges to physical, psychological, social and spiritual continuity. Many authors have recorded the importance for those facing long term illness of developing a coherent narrative, or ‘story’ which explains the persons’ illness, and most crucially, illustrates how it affects them as an individual in the unique context of their own life. In the midst of the potential discontinuity and incoherence of illness, it is suggested, personal narrative coherence becomes very important, however limited and inaccurate others may perceive that narrative to be.

Narrative Coherence

The centrality of a person’s health/illness narrative, the way in which he/she makes sense of unpredictable, potentially distressing and mystifying experience is, many authors suggest, of vital therapeutic potential in helping him/her to adapt to the fundamental uncertainty and loss which progressive illness may engender. Supporting a coherent narrative however presents challenges in the context of a multi-disciplinary and often fragmented health and care system and widespread patient access to internet based, un-interpreted sources of information.

Continuity of Relationship

While multi-disciplinary models of healthcare have been shown to provide the best outcomes, interaction with an evolving succession of health and care workers, with limited and sometimes overlapping agendas, can be a confusing and tiring task. For those whose capacity to communicate is not limited by illness or by language, the task of repeatedly explaining changing personal health and care needs is potentially humiliating, exhausting and demoralising. As care requirements become more complex, and the number of health and care staff involved grows, this burden may become heavier, even as those negotiating illness find their energies and capacity to communicate declining.

Particular Challenges: Rare Disorders

For those affected by a rare disorder, there is evidence that communication with health and care systems can be particularly difficult and discontinuous. The recursive themes which characterise patient experience as identified in a survey of 597 participants by Rare Disease UK include:

- ‘Patients or families have to repeatedly tell their story to professionals involved in their care.’
- ‘Poorly coordinated care, in particular during periods of transition.’
- ‘Poor information provided by the NHS on rare disease, and varying levels of knowledge among staff.’
- ‘Inequalities in treatment around the UK’.

Particular Challenges: Migrants

Migrants with limited local language and knowledge may also have a particularly difficult struggle to convey their individual histories, preferences and needs as their illness evolves and the potential number of health and care workers involved in their care grows. Much work has been done to describe the particular discontinuity and difficulty which cultural and linguistic barriers may add to those with complex illness.

Social Isolation

Progressive illness almost by definition involves some decline in energy and social engagement. There is much evidence of social isolation among those living with long term progressive illness before their withdrawal, due to declining energy, becomes irreversible. Many factors contribute to this. Loss of confidence associated with the changes of illness is one, as is society’s perceived utilitarian value system, linking individual value to financial productivity or ‘usefulness’. The potential effects of social isolation on health outcomes are highly significant in themselves, and the benefits of on-going social engagement and social capital to health have likewise been clearly demonstrated.

Practical communication difficulties contribute to social isolation, and are of particular pertinence among the frail elderly, and in care situations which involve changing health and care staff. The development of personalised records which explain individual communication and care requirements, such as ‘This is me’ by the Alzheimer’s Society have been found to be of benefit in this context.

Cahn, in his widely acclaimed work, ‘No More Throwaway People’, suggests that current health and care models may impose passivity on those in need of supportive care, and stresses the need to preserve, as far as possible, each individual's evolving personhood, and their meaningful interaction with the community in which they live. This view has been supported by repeated studies and has provided evidence for approaches such as Kellehear’s, whose public health based vision of palliative care sees the need to re-involve communities in providing meaningful engagement and social capital for those living with debilitating medical conditions. It is important to understand however, that this engagement may necessitate each affected person or their carers having to individually and repeatedly explain something of their unique communication or care requirements to neighbours, colleagues, friends, volunteers or other community members.

Self-Management

The provision of anticipatory information and advice, and the fostering of self-management knowledge and tools, including red flag tools, has been promoted in a range of regional and national strategies for the management of long term illness. Anticipatory advice changes as illness evolves. Advance Care Planning, the explicit consideration of care preferences in anticipation of declining capacity, has also been shown to be associated for some patients and families with an improved sense of involvement and control in one’s own care, and a better experience of care.

Coordinating and storing this information in a place from where it can be accessed when necessary is a further communication task which requires the involvement of individuals, their carers and their healthcare teams.
Communication Challenges: Family/Carer Perspectives

It is well recognised that the experience of caring for a loved one with life limiting illness can exact a heavy toll on the mental and physical health of the carer(s). Alongside the practical challenges of evolving dependency and the emotional cost of witnessing illness, communication challenges may be complex. Those living with medical conditions are often keenly aware of and distressed by the effects of their illness on those who support them, and a mutual desire by all involved to protect one another from distress may complicate communication.

Cognitive Decline

The work of communicating practical, clinical information, and of explaining unique individual needs and requirements is often shared between those affected and their carers or families. In situations where cognitive decline is a feature of illness, this work increasingly becomes the responsibility of carers and families. The particular onus of caring for someone with progressive cognitive decline may include intense communication challenges, involving the need to explain the fine detail of individual care requirements repeatedly.

Decision making for those with cognitive impairment is similarly fraught with challenge for carers and families. While Advance Care Planning seeks to capture an individual's major care preferences while capacity is intact, it cannot possibly include the innumerable small daily decisions and unforeseen choices which daily life involves.

The need to try to preserve the unique identity of a loved one who is undergoing cognitive decline and to communicate 'who this person was', how they interacted with the world and what defined them, can be painful and exhausting, and fraught with ethical and practical challenges. Research to elucidate and capture the experiences of carers in this regard is ongoing and will, it is hoped, offer vital clues as to how those individuals may be better supported by society.

Thinking Ahead

For carers and families who undertake much of the practical care, there is a need for anticipatory information which allows them to plan ahead and to anticipate and prevent crises where possible. As discussed above, this may involve shared access with affected individuals to information about ‘red flag’ signs, self-management advice or ‘information prescriptions’. The coordination of this information into an easily accessible format is an important task.

The nature of life-limiting illness however, means that anticipatory planning includes adaptation to potentially major loss and change. The tradition of ‘truth telling’ in western healthcare systems favours explicit communication, but the potential emotional impact of the information being given necessitates highly individualised and sensitive interaction. This presents real challenges for all those involved which may be further complicated by confidentiality issues.

Patient-held tools have not yet been shown to demonstrate benefit in such a challenging area of communication, as most research has focussed on patients carrying clinical records, written by professionals, for professionals, in clinical language. There has been much less work looking at the potential role of tools where the content is controlled by the affected individual and/or carer. Very little is known about how such a document might impact on information sharing in this context.
Communication Challenges: Health and Care Professionals

There have been major changes in the organisation of health and care systems over the past 50 years. Foremost among these within the NHS has been the shift away from relationship-based care to more complex models involving greater numbers of individuals and disciplines and a subsequent focus on pathway and protocol based models.

These changes involve both losses and gains and a detailed exploration is well beyond the scope of this report. In 2004, the World Health Organisation (WHO) published ‘The Solid Facts’ a paper which laid out the imperative for health and care professionals to develop palliative care based approaches, including anticipatory and ‘joined up’ models of care to patients facing long term progressive illness. This has been followed by a number of publications by experts in different long term conditions which strongly support this approach.

Continuity of Care

Continuity of Care: Relationship

A recent refocusing on ‘patient-centred care’ implicitly acknowledges that complex healthcare systems have not always evolved with the patient’s needs at the centre. While continuity of care potentially includes continuity of relationship, continuity of management and continuity of information, fragmentation of services may render the first unachievable and all three worryingly difficult to achieve.

At primary care level, GPs are traditionally the interpreters and coordinators of health related information for patients, carers and families. Continuity of relationship within General Practice itself however faces challenges, which include part-time working, bigger practices, and GPs being increasingly burdened with administrative and commissioning roles. Evidence suggests that patients would like more relationship continuity than they are getting and that relationship continuity is linked with better patient and staff satisfaction. GPs report that they are often ‘out of the loop’ in systems which include increasing numbers of specialists . The NI End of Life Care Strategy includes, as a core requirement, the allocation of a ‘key worker’, who will help to coordinate care for each patient thought to be in their last year of life. While the potential value of this is clearly accepted, its implementation in reality is often challenging.

Continuity of Care: Management

This implies a set of priorities and goals and a means of working towards those which are shared by patient, carers and health and care professionals. Given the realities of complex co-morbidity and the multiplicity of teams which may be involved in advising any individual patient, shared goal setting can be very difficult. The re-emergence of generalist practitioners at the centre of care is one important factor which may help this. The development of patient-held tools is potentially a second.

Continuity of Care: Information

Demographic changes mean that the numbers living with long term progressive illness are growing rapidly. WHO has called for a step back from specialty dominated models of healthcare and for greater emphasis on generalist care. Regional and national strategies for long term illness stress the need for coordination and planning at community level.

This necessitates a coherent stream of information between all of those involved in health and care. Between professionals themselves, a number of electronic communication
systems seek to facilitate this, including locally the Electronic Care Record, in Scotland the Key Information Summary, in England and Wales the Summary Care Record and the Royal Marsden’s ‘Coordinate My Care’ model. These systems are built primarily for the information needs of health and care professionals, who must then facilitate the provision of a coherent stream of information to and from patients and carers. From here the dissemination of information throughout the affected individual’s support network is controlled by him/her and those to whom he/she entrusts this responsibility. These last vital steps are the ones on which this project has focussed.

Project Methodology

1. A steering group was constituted by RCGPNI in September 2011.

2. A project plan was formulated which included the development of on-going conversations with individuals living with medical conditions, advocate groups, health and care professionals and carers; this process was to include three large interactive workshops with wide representation.

3. A GP Clinical Lead was appointed in January 2012 to carry out the core work of the project.

4. An initial literature review was completed in March 2012.

5. Contact was made and maintained with a range of individuals, advocate groups, carers groups and healthcare professional groups, via face to face meetings and presentations, email and telephone conversation. Some discussion was also held with patients and carers opportunistically, during the course of clinical work. Workshop one, which involved 141 participants, was held with the support of the Patient and Client Council in September 2012 and focussed on the content and design of the Passport. Workshop two in May 2013 involved 74 participants and focussed on distribution, awareness raising and practicalities around access and usage. Workshop 3 focuses on presenting the completed work.

6. A number of drafts have been developed, evaluated and redrafted, in order to accurately reflect the views of participants. In December 2012 a pilot version was launched, via advocate groups, healthcare teams, GP practices, professional forums and patient involvement forums. 350 pilot Passports were allocated and feedback sought from a range of stakeholders.

7. A second literature review was undertaken to explore the evidence for the emergent tool, which is very different from that originally foreseen. The review is included in this report.

8. As a result of extensive feedback, a final version has now been drafted.

9. Training and awareness raising resources have been developed.

Addressing Current Communication Gaps

The content of the resulting document has been based on understanding the communication gaps in the current process of care from the perspective of individuals who live with progressive medical conditions and their carers. It has taken shape slowly, as a result of an evolving process of discussion, trial, evaluation and adaptation between the steering group, individuals and families and the large group of organisations and agencies involved.
Core/repeated messages from this process include:

- Many individuals confirmed the exhaustion and humiliation involved in recounting their changing care needs and/or basic health details repeatedly to new care staff, domiciliary health and care staff, extended family members, volunteers or friends involved in their care and support.

- Many individuals reported surprise and disappointment that healthcare staff from community agencies, such as specialist nurses, Occupational Therapists or Social Workers do not have routine access to their GP records and may not have basic information about their individual medical history.

- Many report the unpredictable nature of illness-related change and a crisis–triggered approach to healthcare to be difficult, particularly where it involves Out of Hours crises. They would like, where possible, to have anticipatory advice about the illness related problems which are likely to develop and how to respond if these do develop. This is information which may also need to be shared with carers.

- Some are keen to be offered the possibility of planning ahead and of making and documenting healthcare choices, where choices exist. Where Advance Care Plans exist, it is important that they are housed alongside other core information and can be easily accessed by anyone involved in healthcare decision making.

- Similarly, emergency staff are keen to know where Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) documentation, if this exists, might be held.

- Family carers confirm the difficulty they have in managing care of individuals who have communication difficulties due to illness (e.g. dementia, stroke), as their individual care needs and preferences must be explained repeatedly to all new care staff. Carers find it hard to get any respite themselves if they are uncertain that staff understand their loved one's individual needs and resources. They may experience distress due to the difficulty of maintaining the 'personhood' of their loved one, in different care settings.

- Multiple health and care staff can lead to confusion. Patients request a ‘who’s who’ for their healthcare team, so that new healthcare staff can record their name, role, contact details and when and how they should be accessed.

- For those who are migrants, communication may be particularly difficult due to language and cultural barriers. Interpreters are not always available or wished for. A document which contains core person centred information as well as basic health and care information might be of help.

- Those with rare conditions and their families report the distress caused by healthcare staff not having knowledge about their condition or, at times, uncritically accepting the patient or family's expertise.

Emergent Content/Design

- 10 core sections (see below).
- Not all sections needed by everyone.
- Ring binder; allows for updating of information.
- A5 size strongly favoured by patients for ease of carriage.
- Individual customisation of content.
- Summaries, information prescriptions and pre-printed management plans held in section related polypockets.
Key Principles:

- Patient and family owned and largely completed and updated.
- Useful for anyone with complex, progressive illness who require ongoing care.
- Designated keeper (affected individual or carer).
- Added to/modified by healthcare team, in particular by GP practice who provide A4 summaries (which are held in polypockets).
- Simple, legible, concise and brief.
- Most useful where condition or practical care needs are complex.
- Particularly useful where communication impaired by illness or language.
- An electronic multi-platform format for the tool would have further functionality and is recommended, but it is likely that both paper based and electronic formats have a clear role, depending on individual access and preference.

Abbreviated Summary of Content

The title of the communication tool is:

‘What I Need You to Know. A Health and Care Record for Me, My Family and Carers’

It is subtitled: ‘My Healthcare Passport©’

Sections:

1. All About Me

- Individual communication requirements.
- Daily routine, diet, key information, interests. Core values/spiritual beliefs.

2. I Can Complete Many Tasks with Proper Support. This is what I need help with:

- Detail of care requirements: eating, dressing, safety, toileting, minimising pain, equipment.

3. My Health (A4 summaries from GP)

- My medical history.
- My significant allergies.

4. My Medication (Repeat medication summary from GP or Pharmacy)

- Repeat medication.
- Special Instructions (to be updated by pharmacy or healthcare when needed).

5. My Healthcare Team

- Who’s who.
- Who to call.
- When to call.
- How to call.
6. What My Healthcare Team Wants You to Know

- New, evolving information and advice.
- Advice on issues which may need urgent attention.
- Management plans.
- Information prescriptions.

7. Information and Advice About Issues Which May Need Urgent Attention
(Many people will not require any information in this section)

8. My Medical Condition (Information leaflets)

9. My Family, Friends and Carers (Contact details for my support team)

10. Useful Resources: Support groups, websites, books etc

11. In the Event of:

- Advance Care Plans, and where completed, Advanced Decisions to Refuse Treatment (ADRT) or DNACPR.
- Enduring Power of Attorney.

**Training Resources** (available on www.rcgp.org.uk)

‘What I Need You to Know’ is a short film (DVD) explaining the tool, applications and potential impact which includes testimony from Mr Michael Holden, on behalf of the Motor Neurone Disease Association, from Ms Fiona McLaughlin representing the views of carers and from Professor Max Watson and Dr Laurence Dorman on behalf of the RCGPNI.

Guidance notes for professionals, patients and carers are contained within the tool, and explain its usage in simple and accessible terms.

An information sheet for inclusion on patient websites has been developed, and many patient organisations are willing to include this on their websites.

A power point information presentation explaining the tool can be downloaded from the RCGP website.

A further presentation about the project is accessible via the International Primary Palliative Care Network, on the web pages of the International Primary Palliative care network, on http://www.uq.edu.au/primarypallcare/

**Distribution**

Many of the advocate organisations involved in the process have offered to house information about the tool on their websites. They also suggest that their staff and members will advocate its use and explain how the tool can be accessed, completed and used. Specialist nurses and GPs have also expressed willingness to promote usage of the tool. Moving forward, should the passport be made widely available in a printed format then a distribution strategy would need to be developed.
**Evaluation**

There has been an on-going process of evaluation throughout the emergence and development of this tool, during which stakeholders have considered, commented on and contributed to its evolution. A pilot version, which was prepared in December 2012, was widely circulated (350 produced and circulated) for evaluation and feedback on content, layout and design. Small groups of pilot users were recruited by teams within dementia care, and community respiratory care. A small group of individuals who are living with progressive neurological illness have also piloted the tool and have been key contributors to its evolution. Feedback has centred on the ease with which the tool can be completed and used, and on the clarity and relevance of its content. This feedback has led to the development and presentation of the final version in January 2014.

It is very clear, however, that this tool has been designed to be used on a potentially long term basis, and its deeper evaluation will be possible only when it has been used over a substantial period of time. This puts the substantive work of evaluation beyond the timescale of this project. Consequently, the project team have forged links with a number of potential research and evaluation forums. These include:

Usage among carers of individuals with dementia: The development of a research proposal to further clarify difficulties surrounding communication in dementia is being led by Professor Gerard Leavey of the Bamford Institute at University of Ulster and clinicians in the Western Trust Area. This project, if realised, will seek to evaluate the tool over a period of eighteen months, while also looking in depth at the communication challenges involved in dementia.

Usage among those with motor neurone disease: Ms Alison Dick and Dr Collette Donaghy of the Motor Neurone Disease Care Network, NI, are exploring the development of a small research project to evaluate the use of the tool among a small cohort of patients.

Usage among migrant patients: The possibility of developing a project to evaluate and adapt the tool for use among migrant patients in England is being explored, either as a collaborative collegiate healthcare/public involvement project, like the one described here, or as an individual academic research project.

**Conclusions and Recommendations**

This work has described a multiplicity of communication challenges which face those adapting to life-limiting illness, their families and carers and their health and care teams. It has highlighted how changes in the provision of health and care services, from relationship-based to more multi-disciplinary and protocol based models of care involve challenge as well as gain for affected individuals, carers and healthcare professionals.

The generous response by individuals, carers and advocate groups to this project has highlighted the widely felt need to engage with these very real communication challenges and to look creatively at developing solutions.

**End of Life Care Passport**

Amongst the most important learning from this project is a growing appreciation of the multiple communication challenges faced by those who live with life limiting illness on a day to day basis. Accepting and adapting to the prospect of death and dying represents only a small part of this reality, and this adaptive process is highly individual, involving varying explicit and implicit patterns of communication, interspaced at times with periods of denial. In appreciating the need for a wider perspective, the focus of the group’s work
has shifted away from developing an end of life tool towards an exploration of what areas of communication and information are needed by individuals and families to sustain them throughout the illness journey.

During the last weeks and days of life, the emotional and practical work done by patients and families changes in intensity. Participants in this project felt that the introduction of a new communication tool for use in the last weeks of life would not be appropriate and that to be valuable it should be introduced much earlier, with the aim that coherent networks of communication should be well established long before the end of life care phase.

It has, however, been suggested by some participants that introduction of a symptom monitoring tool which would allow carers to report on an individual’s symptoms or needs in the last days of life might be added, when professionals feel it is timely and relevant, to the existing hand held file. This proposal, which would need careful evaluation, will not be possible until the core passport document has been used and evaluated over a significant period of time. We suggest however that it may form the basis of possible future research.

Access/Usability Issues

The communication tool which has emerged is in many ways very simple. Early evaluation suggests that it will not be suitable for everyone who might benefit from its use.

- The need for a designated keeper and the onus on individuals to complete and update the information assumes a level of literacy and a willingness to engage in ownership and control of personal care which not all will share.
- For those where care is carried out only by close family members and small healthcare teams, (where there are few ‘new faces’ involved) the benefits of a written tool may be small.
- Hand-held formats provide challenges for those with sensory (such as visual) or motor impairments, which may not be surmountable.

From those who have been using the pilot tool however, the feedback has been enormously positive, and it is clear that it offers real potential for a new level of partnership working between individuals, carers and health and care services.

Sustainability

In terms of medical economics, current challenges dictate that any new developments must be financially sustainable, and demonstrate cost effectiveness to the system as well as benefit to patients. While long term evaluation remains incomplete, we suggest that this tool may contribute to the sustainability of NHS and social care systems in a number of ways:

- Social capital and community engagement have been shown to impact on disease trajectory for some long term conditions such as dementia, where decline in function may be moderated and the need for nursing care reduced by on-going engagement. In reality as discussed, maintaining social engagement for those facing progressive disability involves many communication challenges. We suggest that individuals and carers need support to manage these challenges.
- Crisis prevention, in particular, prevention of hospital admission, is an aim of much current healthcare strategy work, and both Advance Care Planning and Anticipatory Clinical Planning have been found to be effective in crisis prevention and reduction in crisis admissions. We suggest that this tool will facilitate the introduction of these
concepts, the initiation of potentially difficult conversations and the storage and accessibility of Advance Care Plans.

- In terms of cost, the cost of producing, distributing and updating ‘What I Need You to Know’ will depend to some extent on the numbers using the tool.

E-Formats

The development of an electronic, multi-platform format for this tool is a step which many (particularly younger) patients and carers are very keen to see happen. While adding extra functionality, e-formats would also allow for greater access, by the use of bespoke advanced communication technologies for those facing sensory or motor disability.

The project has engaged with the University of Ulster’s Creative Technology Department. Students there have begun creative design work with great enthusiasm, and within this collaboration there is great potential for future development. We would strongly recommend that consideration be given to furthering this collaboration with the aim of developing an e-tool which offers sustainability, wider access, and future potential to communicate with other healthcare systems.

Rare Disorders

The Consultation Document on the UK Plan for Rare Diseases (2012) suggests that patients help to coordinate their own care, “particularly if empowered through a patient held record, which may be a booklet or an electronic record. Personalised care planning is a means of standardising excellent care for people with long term conditions.”

The patient held record, it is suggested

- ‘Promotes choice and control by outing the person at the centre of the process and facilitating better management of risk.
- Ensures that people, especially those with more complex needs, or approaching the end of life, receive co-ordinated care packages, reducing fragmentation between services.
- Provides information that is relevant, timely and accredited to support people with decision making and choices (for example, supported by an Information Prescription).
- Provides support for self-care so that people can self-care/self-manage their condition(s) and prevent deterioration.
- Facilitates joined-up working between different professions and agencies, especially between health and social care.
- Results in an overarching, single care plan that is owned by the person but can be accessed by those providing direct care/services or other2.’ (Consultation 2012)

There is significant overlap between these aims and the aims of the RCGPNI’s communication tool, which, we suggest, might act as a starting point for work to support those living with rare disease. This group would benefit particularly however, from the development of an electronic multi-platform format, which would allow communication networks between those with clinical and experiential expertise in differing countries, and those living with rare progressive illness.

The Children and Young Peoples’ Passport

Participation activists and interested health and care staff have been exploring the concept of patient held communication tools over a number of years, and many models exist throughout the UK. Many of them, however, offer a snapshot, rather than an evolving picture of individual health needs. In Northern Ireland, Barnardo’s (and the Children

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and Young People’s Strategic Partnership) have been at the forefront of developing a communication tool which has the capacity to reflect an evolving and complex health picture. There are many similarities between this tool’s format and the RCGPs’ work. However, there are also essential differences, for example in the language used and in use of symbols and pictures. We are hopeful that these emergent tools will complement one another and that their potential for flexible content will help to support young people facing transition from children to adult services, a time of particular challenge and change.

Networks and Resilience

The development of a coherent network of information and support, whether from healthcare professionals, family or community is an evolving task which underpins each individual life journey with a progressive long term medical condition. Kellehear has explored this concept in ‘Compassionate Cities’ where he says³:

“Recent studies of communities and how they work (or don’t) show that the most important ties and supports that people successfully employ for themselves are based on simple networks. These may be in cities or in rural areas. They can be suburban networks or ones based on kin. The important element involved in these networks is that people understand how to access and use them, how to communicate effectively within them, and the stability and support people gain from them.”

There is widespread appreciation, from individuals faced with illness to those composing National Strategies, of the core value of support networks, which include both health and care expertise and advice and the support of community. As previously discussed, social engagement and social capital have been found consistently and overwhelmingly, in a range of studies, to be associated with improved outcomes for those living with long term conditions.

Those who display high levels of personal involvement in managing their own health (‘active coping’) have also been shown to have improved health outcomes and this realisation has formed the basis of much healthcare strategy. In the wider context of individual lives, we hope that this tool will support and empower individuals and carers in coordinating their care and facilitating communication within potential support networks, whether family, community, or health and care profession based.

Much work remains to be done in disseminating, evaluating and further developing the potential of this tool, and in further exploration of the questions which it raises about life with long term conditions, and the factors which facilitate resilience among those who live with long term conditions and their carers.

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