Project Evolution

Redesigning Palliative Care in Renfrewshire HSCP, Scotland

Introduction

The Renfrewshire Macmillan Palliative Care Project started on Jan 8th 2014 and is funded by Macmillan Cancer Support until Jan 7th 2017. The project aim is to facilitate the implementation of local and national strategies to support continuous improvement of palliative care in all community settings. The team were tasked with examining the whole palliative care journey, as experienced by patients across Renfrewshire and influence future local developments in palliative care. Team members' role is to listen, educate and facilitate change in order to support health and social care professionals provide seamless high quality palliative care within a culture where palliative care is everybodies business.

Aims and Objectives

Overarching aims:

1. Continuous improvement of palliative care in all community settings
2. Enhance continuity and reduce variation
3. Making palliative care everybodies business

2 key strands:

1. Improving patient experience
2. Increase staff's knowledge and experience through education

Engagement and Findings

From the beginning it was identified that engagement with the public as well as health and social care professionals was important to ensure the success and sustainability of the project.

A variety of methods were used to capture data on gaps, needs and issues in relation to Palliative Care in Renfrewshire HSCP. The main methods were:

1. The Palliative Patient Timeline
2. Climate Surveys
3. Open Space Event

Palliative Patient Timeline

The palliative patient timeline was developed to capture the thoughts and ideas of health and social care professionals from all settings around the challenges and variances in palliative care. It consists of a timeline from diagnosis to palliative then to end of life and is split into the acute and community settings. Participants made their comments on a post it note which was then placed on the timeline where it best fitted. These were then themed by the project team and contributed to the engagement findings.

Climate Surveys

1. Public

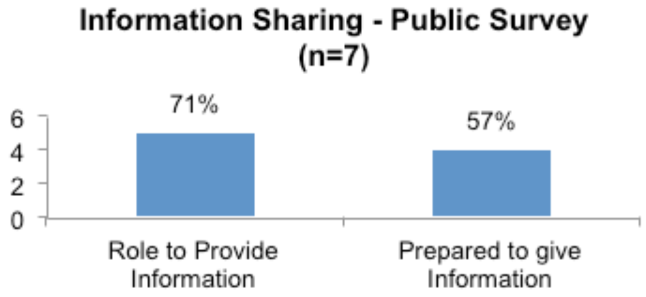
To help understand people's experiences, it was vitally important to hear from the public living in Renfrewshire. To do this, a 'Climate Survey' was devised which aimed to capture an overall sense of palliative care in Renfrewshire currently. This proved to be challenging, bearing in mind all approaches and requests to complete the survey needed to be appropriate and sensitive. It was agreed at the offset that a 'targeted' approach would be inappropriate. Therefore a number of different avenues were tried, from providing a link to an electronic version of the Climate Survey as part of a feature on palliative care run by the local newspaper, to community pharmacy staff providing copies of the survey to any customers expressing an interest in taking part. When the survey closed, 20 responses had been received.

2. Staff

A climate survey was sent to staff across Renfrewshire to get a feel of palliative care locally. An enormous 375 responses were received, respondents included staff from acute, community, care at home services, social care staff, hospice, care homes, NHS24 and the voluntary sector. Demonstrating real engagement and providing a real insight into the current local situation.

Findings from the Climate Surveys

Although numbers of participants for the public survey were small with only 20 surveys being completed, the survey has provided interesting information. 7 out of the 20 respondents stated that palliative care was relevant to their circumstances at this time. When asked in the survey how much of a role they played in ensuring health and social care staff had the information they needed in order to provide care and if they felt prepared to provide this information the following results were obtained:

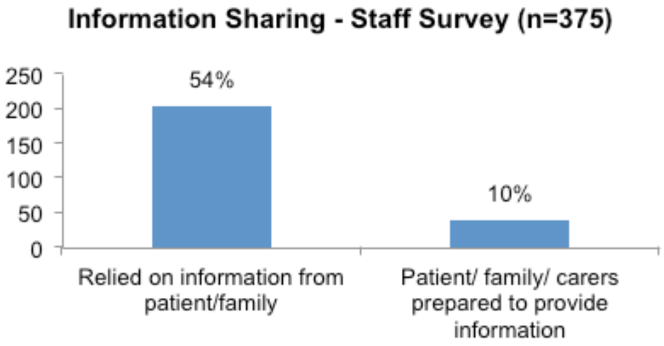


Participants in the public survey then went onto say:

> *I worried I would miss something and there would be negative consequences and it would be my fault. I felt like I was directing care but without the right information to do it well.*

> *It was always up to us to ensure that everyone knew what was happening, tell to DN what the GP said, tell the GP what the consultant said. It never felt like anyone other than us had the full picture.*

From the staff perspective, (n=375) when asked if they relied on the information provided by patients and their families and if they felt that patients/families/carers were prepared to provide the information, the following results (which strongly correlate with the public's response) were obtained:



Another interesting fact to come from the public survey was when asked how difficult it was to find their way around all the services, 3 (44%) felt it was very difficult going on to say:

> *Finding services and information is one of the most difficult parts of caring.*

With regards to the staff survey a large number of comments (n=74) were received when staff were asked where they felt inequities existed in palliative care in Renfrewshire. (see wordle on poster) The top five themed responses were:

- Inconsistency in approach/lack of joint working/poor communication
- Non-malignant conditions treated differently
- Limited hospice availability
- Lack of resources and staff trained in palliative care
- Inconsistent approach taken by GP practices

The Open Space

Open Space is a facilitation method in which individuals can identify specific issues on a given topic and self select into discussion groups with others who are also concerned with that issue. This method was used to help shape the project direction and inform how we focused the aims. This event took place on 5th March 2014 with 75 representatives from the multi-disciplinary team across all settings (from acute and primary care) and from the public/volunteers sector.

A large number of ideas were shared on the day and a number of priorities identified. Due to the level and variety of engagement a number of the priorities were beyond the scope of the project or already being addressed as part of national and/or board priorities. (e.g. 24 hr access to services/ reducing inappropriate hospital admissions/support to care homes)

The project team then considered the priorities identified alongside the outputs from our wider engagement and in partnership with our steering group, formalised an action plan around the following themes:

The 4 themes that emerged from our engagement:

1. Lack of consistency and equity
2. That patients and their families are often the co-ordinators of their own care and that this can be burdensome
3. That health and social care services have become too big and unwieldy that people struggle to navigate them and often have no idea where to turn for support and information. The same can also be said for staff, take us out of our geographical area that we know well or our own area of specialty and we do not know what is available and find it very difficult to meaningfully signpost people
4. That staff have difficulties in finding and accessing training locally and across health board area

Driven by these themes the focus for our work led to the development of 4 key outputs.

Outputs

1. Standard Response for patients with new or changing palliative care needs

The aim of the standard response model is to reduce inequalities in service provision through adopting a **standard response** when palliative care needs are identified whilst maintaining an individual, personalised approach. This approach promotes **a person centred emphasis** and the use of **holistic person centred tools** to encourage a proactive approach to peoples changing needs. The tools at the heart of the standard response are:

- Concerns Checklist and Care Plan
- Carers Support Needs Assessment Tool
- About Me and My care

Being set within current Gold Standard Framework Scotland meetings provides an opportunity to refresh and enhance the current multidisciplinary team (MDT) Gold Standards approach by facilitating coordination of care. This approach also aims to widen participation in a monthly MDT (bringing in a social care professional) to improve communication, effectiveness and efficiency and to reduce inequalities in service provision by widening knowledge of resources and services available (using the **Electronic Concerns Checklist Resource**).

Coming soon….
The standard response is currently being piloted in 3 GP practices in Renfrewshire, findings will be reported later this year.

2. ‘About Me and My Care’ Pack

‘About Me and My Care’ is a resource for patients and their families, which was developed to provide information to help with co-ordination of care. The pack is split into two sections each contain either information or resources to help with co-ordination of care.

Pack Contents

About Me (resources)	About My Care (information)
My Questions	Useful Contacts
My Appointments	Information for Carers
My Care- Who is involved and how to contact them	Finances-Costs and Benefits
My What Matters to Me	Going into Hospital
My Thinking ahead and making plans	Who Provides Palliative Care?

3. Electronic Concerns Checklist Resource

The electronic Concerns Checklist Resource (eCCR) is a signposting and information tool designed to support Holistic Needs Assessment by assisting health and social care professionals when helping people manage concerns they identify using the Concerns Checklist. It contains information for professionals and more importantly self management resources for people. To ensure ease of navigation of the eCCR, links to internal (within document) and external resources are intuitive and easy to use regardless of ability to use electronic devises. This resource will assist with person centred care planning and is intended to be used openly with the person so that a collaborative approach can be taken in the search for a way forward with a particular problem. Pages can be printed that the person might find particularly helpful. As this resource continues to develop we will link in with NHS 24 and ALLIS who are working on a National Service Directory, and longer term we aim to have this resource available to the public as well as professionals.

4. Palliative Care Training Calendar

The Training Calendar was developed to make it easier for all health and social care professionals within Renfrewshire to find out what palliative care training is available across NHS GG&C. The calendar pulls together all the different educators' sessions into one site. The calendar also provides brief information on training content, who should attend, where the training is held and when it's on. To date this remains the only NHS GG&C training calendar to capture all this information.

Acknowledgements

The success of our project would not have been possible without the help and expertise of the following:

- Macmillan Cancer Support.
- Bristol Haematology and Oncology Centre at the University Hospital Bristol NHS Foundation Trust who developed a service directory which was adapted by NHS Ayrshire & Arran. We then adapted this resource for NHS Greater Glasgow and Clyde
- Health and social care professionals within NHS Greater Glasgow and Clyde, Renfrewshire Health and Social Care. Partnership
- Improving the Cancer Journey Glasgow team.

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