Transforming Care After Treatment (TCAT)

East Dunbartonshire Council and Health and Social Care Partnership.

Macmillan TCAT Pilot Project

May 2018

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Acknowledgements

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- Turret Medical Centre

- Regent Gardens Medical Centre

- Park Surgery

- York Place Medical Centre

- Ashfield Medical Centre

- Denbridge Medical Centre

- Kessington Medical Centre.

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The statistics in this report are the results of a self-evaluation carried out by the project lead officer with support from the WOSCAN lead. The views expressed in this report do not necessarily represent those of WOSCAN, Edinburgh Napier University or Macmillan Cancer Support.

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Executive Summary

More people are surviving and living with cancer and it's important that we recognise that during recovery patients require support in living well beyond cancer and to self-manage their health. In support of this, the East Dunbartonshire Transforming Care After Treatment project undertook to test the use of a personalised outcomes-focused support plan for people with cancer which will enable the latter to set goals and clarify what they can expect from a range of services. The intention of this programme is to improve and imbed new pathways, enhance professional practice and develop peer initiatives rather than focussing on the development of new services.

The Macmillan Holistic Needs Assessment (HNA) was used as a to way clarify what is important to people affected by cancer and to build confidence and knowledge of primary care staff to better understand and support the social needs of patients living with cancer. This will provide a more appropriate and interactive tool for care planning than currently included in the established Cancer Care Reviews (CCRs).

Whilst the project promoted the HNA /concerns checklist, uptake was slow and in some cases resistance to change, from participating GP Practices was not considered within the initial project design. This has added a further layer to this pilot programme implementation which was not previously accounted.

The original guidance was open to interpretation and following review it was agreed to revise and simplify the HNA pathway, guidance and the main focus of the project turned to undertake and promote a change in (practice) behaviours and new approaches through a test of change approach.

Furthermore, upon review of the challenges and risks of the project, feedback suggested that CCRs were not being conducted in a consistent manner across the test sites, which sequentially was affecting the pathway to implementing the HNA.

Collating the learning from a range of long term conditions initiatives which were simultaneously being developed within East Dun HSCP has enabled the TCAT project lead to understand the barriers and attitudes to both engaging with and to introducing new practice methods within Primary Care. This has enabled the TCAT Project Lead to revise the process of engagement, which started to see positive outcomes for implementation and ultimate sustainability of the East Dunbartonshire TCAT project.

To that end, in order to provide a consistent service to all cancer patients within primary care, we will take the learning from this TCAT project to ensure the delivery of high quality CCRs which include a HNA and other elements of the cancer care toolkit. By disseminating the HNA training to all East Dunbartonshire GP practices, using templates and pathways that mirror the management of other long term conditions, we aim to embed the approach and embrace community cancer care. Additionally, members of the East Dunbartonshire Working Group will be invited to form a local strategic Long Term Conditions Steering Group, ensuring cancer is high on the agenda for the Health and Social Care Partnerships (HSCP) business plan.

1. Introduction

This is the overall report regarding the East Dunbartonshire Transforming Care After Treatment Project (for the purpose of this report will be referred as TCAT) which was carried out between 2016-2018. It is one of 25 projects across Scotland (seven of which are led by local authorities) looking to transform the approaches of how people are supported following active treatment for cancer.

The project was part of the TCAT programme, a five year programme (2013-2018), funded by Macmillan Cancer Support in partnership with the Scottish Government, NHS Scotland, Third Sector organisations and Local Authorities. The programme focuses on supporting people

affected by cancer by recognising that to respond to the increase in the numbers of people diagnosed with cancer and the advances in treatment which has resulted in more people living with and beyond cancer, it is necessary to develop new ways of providing support and aftercare.

2.   Context

In 2015, a successful joint application was made by East Dunbartonshire Council and the then East Dunbartonshire Community Health Partnership (CHP)[1] to the TCAT Programme Board. The application proposed a project to be delivered across the local authority area which supports adults who had been affected by cancer, through the use of a planning process and the HNA tool. In doing so, the social needs of those people affected by cancer will be identified, prioritised and links to support within their own community will be established. The application proposed to meet TCAT's aims of;

- working together with people affected by cancer
- inform the discussion on the re-design of services.

The East Dunbartonshire TCAT pilot project was established to lay the groundwork to identify, support and empower people affected by cancer, which it is anticipated will reduce social isolation, to improve pathways following discharge from hospital and to establish better networks and co-ordination of support within and around local communities.

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[1] The East Dunbartonshire CHP became a Health and Social Care Partnership (HSCP) in September 2015

The primary location for this approach is with GP practices, and to that effect 7 (41%) of all GP practices in East Dunbartonshire expressed interest in partaking in the Macmillan TCAT project. All practices agreed to be part of this pilot project in shaping and informing the content, delivery and outcomes for community based cancer care support.

The project is led by Programme Lead Officer, Connie Williamson, overseen by Project Manager, David Radford, standards of service and governance is overseen by the East Dunbartonshire Cancer Steering Group.

3:   The Approach

The East Dunbartonshire TCAT pilot project introduced a social prescribing methodology using the Macmillan Holistic Needs Assessment (HNA) within a cancer care review (CCR) structure and signposting to local third sector organisations. The project has spanned over a three year time-frame in total with the main preparatory work being carried out in the first 2 years until March 2017. It was anticipated that between 50-100 cancer patients would partake in the pilot project over the final year of the pilot, which in essence was the operational period. This report contains the overall findings together with patient outcomes and recommendations.

The approach also recognises the importance of factors such as community capacity building, co-production, good mental health and wellbeing, social capital and addressing the wider determinants of health.

Developing and implementing the social prescribing element of the project was a specific aspiration set out in supporting Primary Care to promote better self management of long term conditions (LTCs).

The development of the project took 2 years to establish, with the initial 16 months devoted to planning coupled with strategic discussions with the East Dunbartonshire Cancer Steering Group. The latter 8 months were spent recruiting and training seven test GP practices for the pilot. The TCAT Operational Group representing General Practice, Social Work, Third Sector agencies, West of Scotland Cancer Network (WoSCAN), Macmillan and Public Health Improvement staff, was chaired by the TCAT Project Manager. The group agreed specification, outcomes, referral process and supported the TCAT project lead to address any emergent issues in operational management.

The operational phase of the project officially launched in April 2017 and spanned a total of 12 months.

4.   Evidence of need.

The best available localised data for East Dunbartonshire is provided by the Scotland Prevalence Quality of Outcomes Framework (QOF). This indicates that for the period April 2013 to March 2014 there were a total of 2,765 East Dunbartonshire patients registered as having cancer across the 17 GP practices within this area. This equates to a prevalence of around 2.5% of the total population of around 106,000 within this authority. From this number, 423 people had received a diagnosis of cancer within the preceding 15 months.

Additionally, figures from the Scottish Cancer Registry show that 640 people in East Dunbartonshire (including 3 aged under 16 years) were diagnosed with cancer during the year 2012.

It was recognised in East Dunbartonshire that there may well be gaps in cancer-related data therefore one of the objectives of this project would be to improve the availability and accuracy of local information.

There is local evidence that people with cancer can experience greatly reduced social activity as a result of treatment and periods of ill-health:

- a series of consultation events with service users and carers during 2013/14 co-organised by Social Work, the Community Health Partnership (CHP) and East Dunbartonshire Voluntary Action (EDVA) under the Ageing Well strategy produced a common theme that when people became unwell they were unable to stay connected to the community.

- the cancer work stream of the NHS Greater Glasgow and Clyde (NHSGGC) clinical services review (2012/13) on isolation due to ill-health (including from the workplace) and how to avoid a breakdown in social links and rebuild contacts.

- a strong theme arising from NHS Greater Glasgow and Clyde work streams has been that although patients were satisfied with the acute services they received they felt that there was less emphasis post-treatment on signposting them to services within the community.

Emerging evidence suggests that encouraging and supporting people with any long term condition including cancer to self-manage at home, is dependent on them acquiring the knowledge and confidence to access support. East Dunbartonshire HSCP held a protected learning event in 2014 for long-term conditions which highlighted the limited knowledge of community resources amongst GPs and other primary care staff and the need for identified points of contact into the third sector and a local directory of health improvement and other services.

5:   Training

A core output from this project was to build the capacity and confidence of:

- Primary care staff working within general practice.

- Those working in the voluntary and third sector.

The TCAT pilot project provided HNA training to Primary Care practice staff coupled with third sector partners who may have contact with cancer patients and their families through-out their cancer journey. Six practices sent staff representation to attend a half day training course provided by Macmillan. One practice received information and update on site due to other commitments. The training was delivered by Macmillan trainers and addressed the practicalities and assumptions that health professionals may have when discussing sensitive and often emotive issues that cancer patients may be experiencing. The training focused on a holistic approach to care planning with the use of HNA ensuring that people's physical, emotional and social needs could be identified by the patient themselves and then met in a timely and appropriate way (appendix 1).

6:   Social prescribing

A promising approach to the management of long term conditions is 'social prescribing'. Social prescribing is a form of 'co-production' that involves linking patients with non-clinical activities, typically delivered by voluntary and community groups, in an effort to improve their sense of well-being. This approach offers GPs a referral option that can operate alongside existing treatments to improve health and well-being. Social prescribing can take on many forms but is generally used to provide psychosocial and practical support for people with a wide range of problems and issues associated with long term conditions which include cancer. Within East Dunbartonshire there is a wealth of community activities including;

- health walks
- financial advice
- health education

- peer support groups
- activity programmes
- wellbeing services

It can be difficult for busy healthcare professionals to realistically understand the full potential of options available for cancer patients in their local areas. The TCAT pilot opted to utilise a signposting role within a local third sector context; incorporating The East Dunbartonshire single point of contact Information Line referred to as OPAL which is available to all adult health service users (16+) in East Dunbartonshire. OPAL puts people in contact with a wide variety of information and services, from social and leisure activities through to Social Work and Voluntary Sector services. Practices will utilise this service by signposting patients to OPAL once they have completed a HNA. This process is included in the Cancer Patient Pathway (Fig 1)

7: The TCAT Project

The following sections describe the aims, objectives, processes and methodologies used in the TCAT project.

7.1 Aims

The overarching aim was to lay the groundwork for an infrastructure to identify, support and empower people affected by cancer and those who work with people affected by cancer to:

- Reduce social isolation.
- Improve pathways from hospital and build community networks through social prescribing.

7.2 Objectives

The objectives for the project are to:

- Improve the knowledge and skills of cross sector staff.

- Build local evidence of the benefits of a holistic approach for patients and health professionals.

- The mapping of assessment tools and developing a common assessment tool for practitioners (utilising OPAL as a single point of contact).

- Develop peer led support groups to empower people to share learning and experiences.

- Improve pathways between primary and secondary care.

- Develop a referral pathway that enables people affected by cancer to access key community supports and services.

- Gain authority wide support for sustaining and rolling out the pilot.

7.3   Process

Pilot practices were asked to indentify cancer patients through their own practice cancer register. In line with best practice, all cancer patients should be offered CCR. The CCR is usually carried out by the GP or practice nurse within six months of the practice being notified that the person has a cancer diagnosis. A CCR is a holistic conversation that assists an individual to raise any issues relating to their cancer or treatment that are impacting on their quality of life or wellbeing.

The CCR is part of the Recovery Package, a set of key interventions which can greatly improve outcomes for people living with and beyond cancer. The Recovery Package was developed by the National Cancer Survivorship Initiative (NCSI) in partnership with Macmillan Cancer Support.

The HNA can be used as part of a CCR or as an independent tool. Use of the HNA provides an opportunity for the person living with and beyond cancer to think through their needs and, together with their GP/Practice Nurse to make a plan about how to best address these needs. Practices were then asked to record a minimum data set for the purpose of the evaluation and reporting of the project.
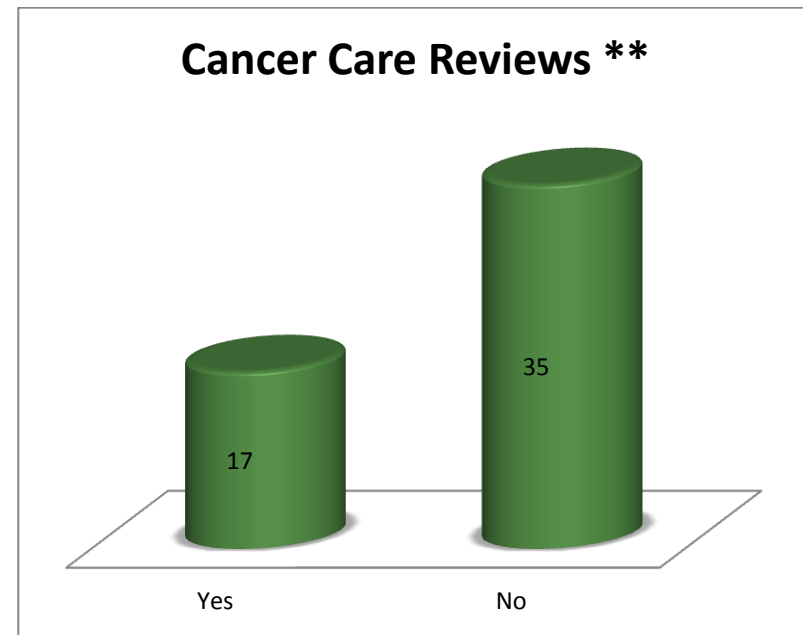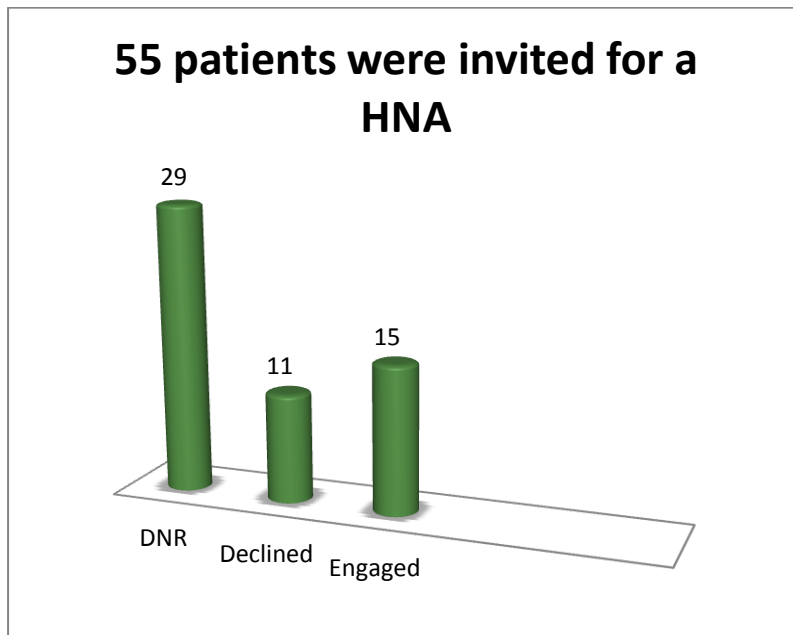
7.4   Methodology

The methodology that was used to evaluate this project included a mixed methods approach of quantitative data collection and focus groups.

The following processes to capture data.

1. **The Minimum Data Set**. This data was collected for every individual patient/user that was identified for a CCR and/or a HNA and uploaded onto Excel by TCAT Programme Lead Officer to be analysed.

2. **The HNA outcomes data**. This data highlights the issues raised on the patient concerns checklist which is completed prior to the CCR uploaded onto Excel by TCAT Programme Lead Officer to be analysed.

3. **Focus groups with practice staff**. Feedback and discussion on the success and challenges of the pilot process within a practice environment facilitated by the Programme Lead Officer and used by improvement methodology.

8:   Evaluation Findings

From April 2017 – April 2018, 52 patients from Primary Care and 3 patients from third sector organisations, were identified to participate in the project. This equated to equal numbers of women and men of varying age. Of this cohort, 15 people (27%) fully engaged in at least one HNA consultation (6 male & 9 female). 11 declined a HNA, 29 did not respond to the invite, 7 people were directly referred to community-based activity programmes such as Live Active (NHS exercise programme) and local walking groups.

55 patients were invited for a HNA

DNR	Declined	Engaged
29	11	15

**Cancer Care Reviews **

Yes	No
17	35

17 Patients had received a CCR, 35 did not receive a CCR.

**Please note, this data does not state that patients were not offered a CCR.

From the returned data, 35 (67%) did not receive a CCR. It is difficult to access from the data if patients refused, did not attend a CCR or were not offered a CCR.
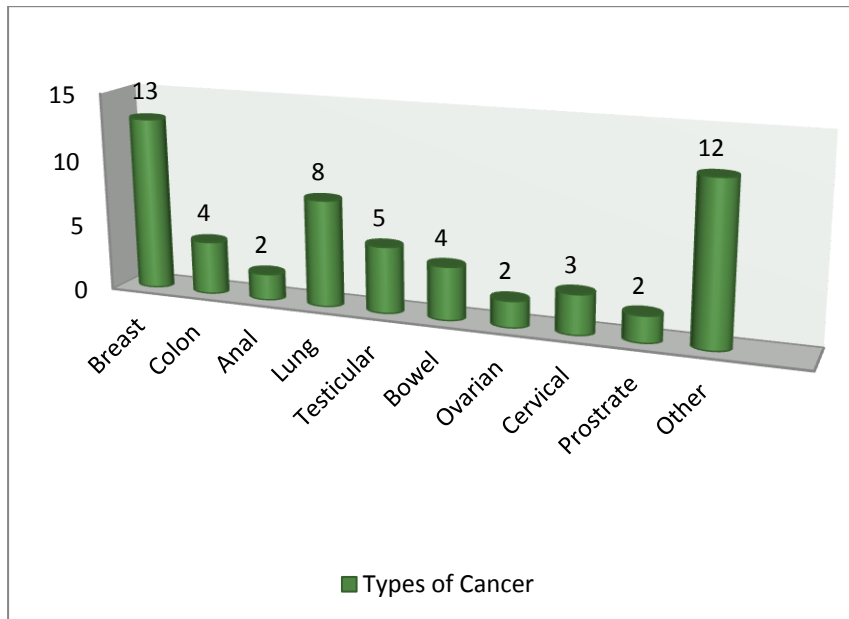
Of the 55 patients invited for a HNA, Breast, Lung, Testicular and Bowel were the most prevalent cancer diagnosis.
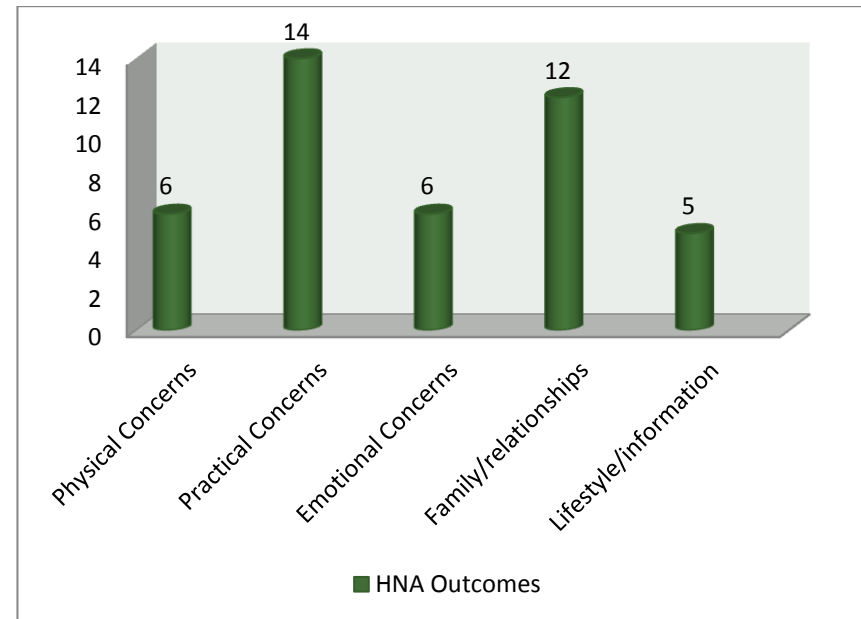
From the 15 engaged patients, practical concerns and family and relationships concerns were most prevalent.

Additional data/information:

- The mean age of patients identified for a HNA is 58 years old.

- An equal number of DNR's were recorded for both men and women.

- 7 patients were referred directly to physical activity programmes

- 6 patients were sign posted to OPAL.

- 7 patients declined as they felt they had the support they needed at the current time.

9:   Improvement Methodology

As a result of low uptake and feedback, routine improvement methodologies concerning the processes and systems were implemented as part of a reflective learning approach. A four stage test of change cycle of; Plan, Do, Study, Act **(**PDSA**)** provided a framework for developing, testing and implementing changes to the project guidance and in the design of a refreshed Cancer Patient Pathway.

The four stages of the PDSA cycle are:

Plan – the change to be tested or implemented (Project guidance)

Do – carry out the test or change (present new pathway for comment)

Study –collate feedback from practice staff on the effectiveness and interpretation of the new pathway.

Act – plan the next change cycle or full implementation.

As the project developed, several challenges arose which led our focus in a different direction.

These included:

- Mapping out the process/system to identify whether there are potential areas of improvement.

- Considering the appropriateness of the original driver diagram.

- Incorporating earlier engagement for a review to test whether the guidance and patient pathway clearly defined.

- Undertaking a consistent implementation of CCR's – are these implemented consistently across all practices, (are outcomes measured, are missed appointments followed up)?

- Confirming key messages – do all colleagues know and understand what these are?

- Utilising the Macmillan toolkit – is this used, when, by whom, what are the outcomes?

- Identifying additional training - are colleagues comfortable in their knowledge around the needs of people with cancer in a community setting?

PDSA outcomes – The PDSA cycle highlighted that the original guidelines were:

- Lengthy and was open to interpretation.

- Inconsistently delivered due to this staffing issues impacted on the delivery of the project.

Changes adapted

- The driver diagram was simplified, updated and reflected the new achievable outcomes and ambitions.

- A clear simple cancer patient pathway was adapted and improved.

- CCR templates will be co-designed with primary care.

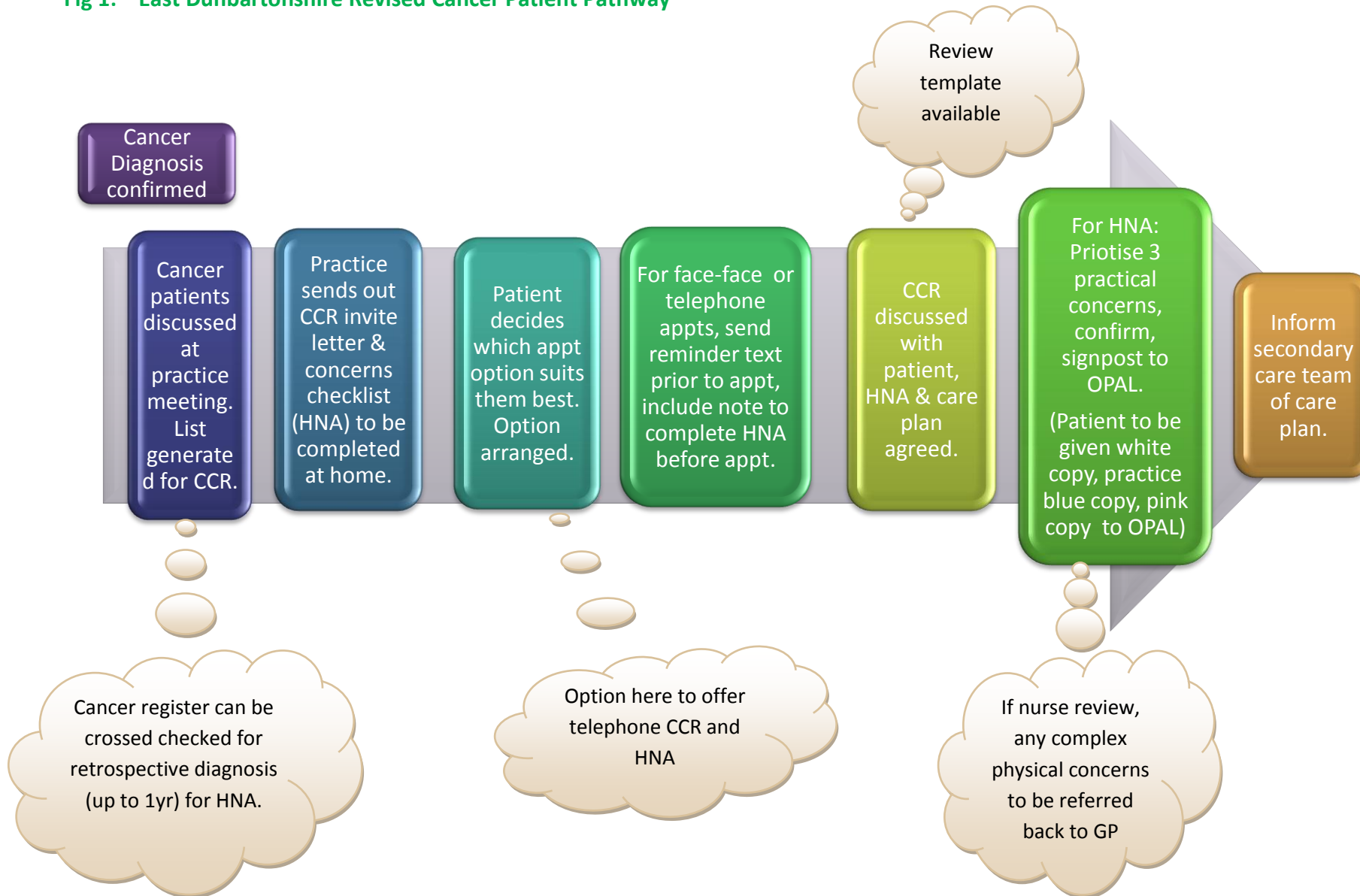- CCR toolkits approved to aid consistent reviews across the authority.

10:   Findings

Findings suggest that CCRs are currently not being conducted in a systematic and consistent manner within Primary Care across East Dunbartonshire. A key issue that has been identified is there is a lack of clarity and guidance about information that should be discussed within a CCR. The review was embedded within some General Practices as part of the 2006 Quality and Outcomes Framework (QOF) of the General Medical Services (GMS) contract; however this contract changed in March 2016. Following this change, the guidance regarding the cancer care review was relatively diluted and became open to interpretation asking for a cancer review 'to cover the patient's individual health support needs' and 'the co-ordination of care between services' (NHS GGC 2016). The review is required within six months of the patients practice being notified of a new cancer diagnosis. There was little information about the content of these reviews and if and how they contribute to the overall management of cancer patients.

In summary, project findings suggest that:

- Primary Care is eager to play a key role in supporting people beyond the cancer diagnosis.
- The range of social issues people face when living with and beyond cancer, are best addressed with a structured approach that is person-centred utilising a social prescribing approach.
- A Primary Cancer Care framework is needed to ensure CCR's and HNA's are consistently assessing the needs of patients affected by cancer (See Figure 1 for patient pathway,) and are embedded into practice.
- CCRs could align with the practice nurse's remit of chronic disease management.

- Structured continual support and engagement with Primary Care will see positive outcomes for implementation and ultimate sustainability of the East Dunbartonshire TCAT project.

Fig 1: East Dunbartonshire Revised Cancer Patient Pathway

Cancer Diagnosis confirmed

Cancer patients discussed at practice meeting. List generated for CCR.

Practice sends out CCR invite letter & concerns checklist (HNA) to be completed at home.

Patient decides which appt option suits them best. Option arranged.

For face-face or telephone appts, send reminder text prior to appt, include note to complete HNA before appt.

CCR discussed with patient, HNA & care plan agreed.

Review template available

For HNA: Priotise 3 practical concerns, confirm, signpost to OPAL. (Patient to be given white copy, practice blue copy, pink copy to OPAL)

Inform secondary care team of care plan.

Cancer register can be crossed checked for retrospective diagnosis (up to 1yr) for HNA.

Option here to offer telephone CCR and HNA

If nurse review, any complex physical concerns to be referred back to GP

11:   Challenges and limitations of the programme:

- Staffing issues, there were year on year, 3 new project lead officers due to 2 members of staff moving onto to new posts.

- GPs were out of contract which no longer focused on the QOF framework.

- A limited time (1year) to test and embed the project objectives.

- Challenge practice attitudes to a different way of working with competing agendas.

- Primary Care capacity, 2 practices failing to initiate the pilot due to internal staffing issues.

- Interpretation of the original guidance was varied, leaving some practice nurses feeling overwhelmed and under pressure.

- Low initial uptake of CCRs and HNAs.

- The existing community Assets Map project is currently suspended due to IP address expiry. The Map will be back online imminently.

12:   What did we learn?

Through the Macmillan network, we know that the HNA within a CCR process works well. There is good evidence across other TCAT projects that support this approach but clear guidance around CCR's is an important factor to successfully establish and implement a holistic person centred approach to cancer care in the community.

Through testing this approach we have had the opportunity to:

- Refocus and articulate clear guidance for Primary Care staff to support cancer patients.

- Collate the learning from current initiatives in formulating a sustainable local framework for social support.

- Ensure that the pathway for the person with cancer links between both acute and primary care sectors, and in addition refers to community services where appropriate.

- Adapt a pathway that identifies key Third sector agencies who can offer tailored support for finance, advocacy and carer support (OPAL).

- Plan training and awareness-raising across statutory, voluntary, third sector and people with cancer.

- Utilise the major opportunities provided through the integrated East Dunbartonshire HSCP to achieve synergies across professional practice.

- Build recognition that cancer can be classed as a LTC and should be included in the LTC strategy to improving people's outcomes and support better self management.

Personal reflection of the Programme Lead Officer

- Throughout the term of the project, there had been unexpected hurdles, challenges coupled with valuable learning and insight. Important learning and guidance came direct from practice staff in the form of feedback, suggestions and focus sessions. This evidenced a strong desire to adopt a holistic approach to supporting cancer patients within the community.

- From an operational management context, having 3 Programme Lead Officer's throughout its lifespan presented significant impact and setbacks in fully establishing the project objectives and outcomes. Project management is a skill that takes time, patience and perseverance. It requires constant analysis of setbacks, failures and implementation of the lessons learned which in itself is time

consuming. Further, strong, supportive relationships with GP practices are vital to establishing new frameworks or models for delivery and these take time and commitment to engender.

Senior management recognition is of the utmost importance for the development of the project. Enabling the Programme Lead Officer to become involved in the new GP cluster meetings and Locality Planning Groups has been of significant benefit in influencing Primary Care colleagues and cementing the learning and approach from the project.

13:   Feedback and Comments

"We felt as a practice that we hugely benefitted from testing this approach. Being involved in the pilot enabled us to contribute to the development of best practice and share our knowledge and understanding of practice based approaches."
 TCAT Practice Manager.

"The original guidelines were a bit confusing and I was too busy to ask, to be honest I felt under pressure and this reflected on our involvement. With the new pathway it does look doable, change always takes a bit of time".
TCAT Practice Nurse*.*

"Although we only did a handful of HNA's, I did see benefit to our patients, I would be happy to see a better pathway that we (as a practice) could embed into how we support our cancer patients."
TCAT Practice Nurse.

"We did try to implement this, although some of our cancer patients already had received a HNA at the Beatson, but we made sure they knew we had an open door approach if they felt they needed more local support. I fully support the new guidelines and pathways to clarify the support we can offer in general practice".
TCAT GP.

"This was a challenge right from the start, although we attended the HNA training and fully supported this approach, we were unable to implement due to staff issues and other priorities for the remaining practice nurse. We look forward to seeing the framework working with you in the near future".

TCAT Practice Manager

"This is something I am really interested in. I am already seeing the benefit to some of my LTCs patients who are using community assets as a means of support through the social prescribing pilot, it has been life changing for them".

TCAT GP

14:   Recommendations

To improve patient experience and outcomes we recommend:

- The learning from this project will inform plans to support primary care to deliver high quality CCR's to their local populations. By mirroring how GPs manage other long term conditions, through 'templates' (within the GP software), a toolkit consisting of clear guidance for CCR's, HNA's/care plans and simple pathways will be developed for use across East Dunbartonshire General Practice. This will allow clinicians in primary care to keep track of the different elements of a patient's recovery. It enables the quick capturing of information about an individual that is relevant and important to them and means the clinicians seeing the patient will have that information at hand to maximise the care/support given to the patient.

- The TCAT Operations Group will merge and form a LTC's steering group to share best practice and to plan and inform future planning and implementation of local strategic plans and Joint Health Improvement Plans.

- That where possible, the TCAT Programme Lead Officer is linked into GP Cluster Groups and Locality Planning Groups.

- Continual monitoring of data on the uptake of cancer screening by GP practice (collected under the Detect Cancer Early programme) in order to identify where there has been a lower uptake and where we need to provide assistance to improve this in order to strengthen a preventative approach.

Final words

A commitment to continue with the learning and approaches determined from this pilot has been endorsed by the HSCP Senior Management Team;

To improve cancer patient experience and outcomes, we (The HSCP) will take learning from the TCAT project to support primary care to deliver high quality Cancer Care Reviews (CCR), including a Holistic Needs Assessment (HNA), to our local populations. The Cancer Patient Pathway will be integral to delivering integrated care that extends from presentation and diagnosis through to palliative care and living with and beyond cancer as a long term condition.

Derrick Pearce, Head of Community Health Care Services.