Transformation Partners in Health and Care

CLCH ACADEMY
Experts in Community Healthcare

NHS
England
London Region

# Transformation Partners
## in Health and Care

Insights from a cancer community of practice, collaborating and working across organisational boundaries to improve patient experience.
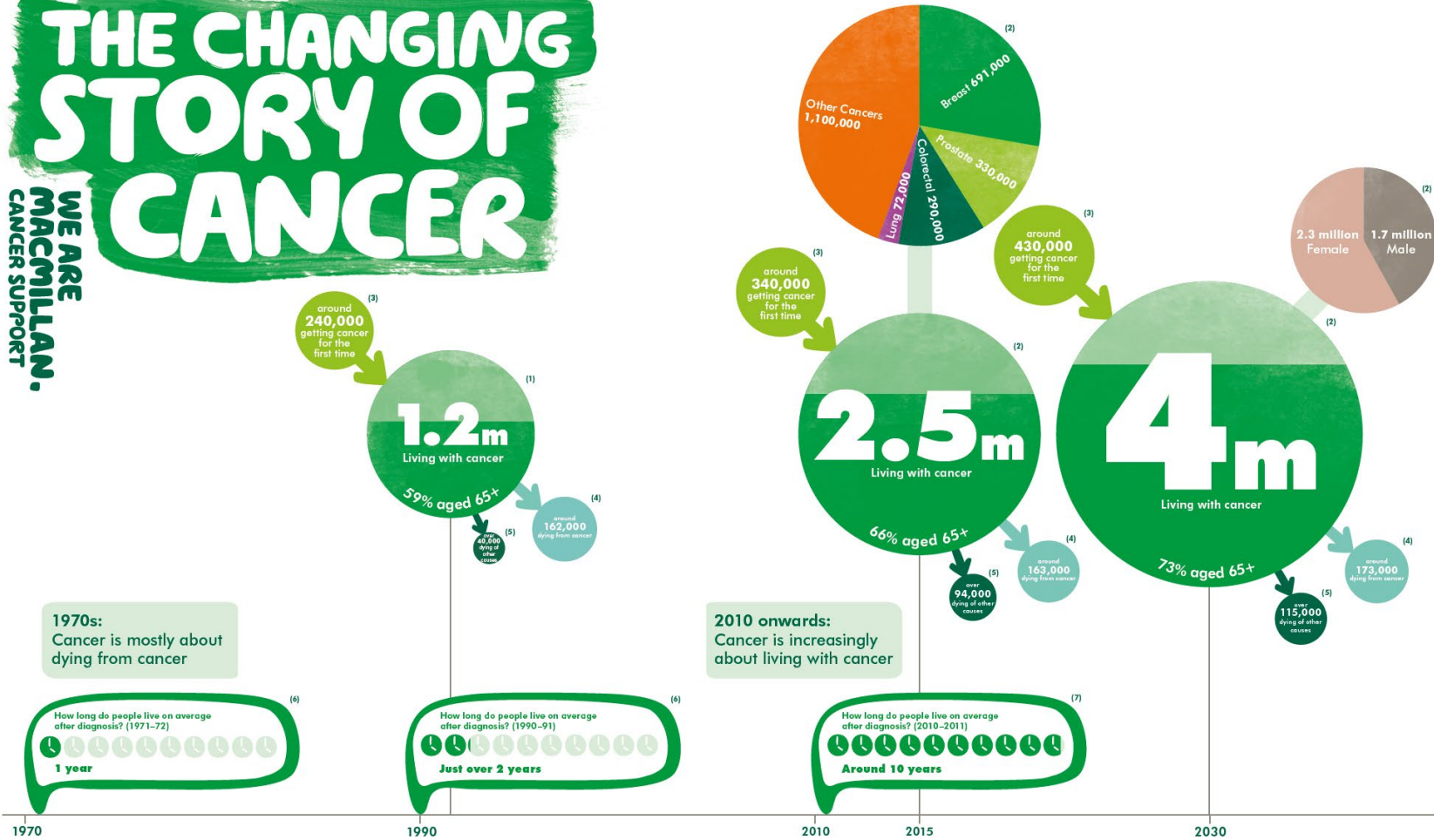
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# Background

# THE CHANGING STORY OF CANCER

WE ARE MACMILLAN. CANCER SUPPORT

Other Cancers 1,100,000
Breast 691,000 (2)
Prostate 330,000
Colorectal 290,000
Lung 72,000

2.3 million Female (2)
1.7 million Male (2)

around 240,000 getting cancer for the first time (3)

around 340,000 getting cancer for the first time (3)

around 430,000 getting cancer for the first time (3)

**1.2m** Living with cancer (1)

59% aged 65+

around 162,000 dying from cancer (4)

over 40,000 dying of other causes (5)

**2.5m** Living with cancer (2)

66% aged 65+

around 163,000 dying from cancer (4)

over 94,000 dying of other causes (5)

**4m** Living with cancer

73% aged 65+

around 173,000 dying from cancer (4)

over 115,000 dying of other causes (5)

**1970s:**
Cancer is mostly about dying from cancer

**2010 onwards:**
Cancer is increasingly about living with cancer

How long do people live on average after diagnosis? (1971–72) (6)
**1 year**

How long do people live on average after diagnosis? (1990–91) (6)
**Just over 2 years**

How long do people live on average after diagnosis? (2010–2011) (7)
**Around 10 years**

1970    1990    2010    2015    2030

The area of each circle is proportional to the number of people.
For access to the Macmillan research listed in this graphic, please visit www.macmillan.org.uk/research

1 Forman D, et al. Cancer prevalence in the UK: results from the EUROPREVAL Study. Ann. Oncol. 2003. 14: 648–654.
2 Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010–2040. Br J Cancer. 2012.107: 1195–1202. (Projections scenario 1). 2015 data is based on 2010 and 2020 rate. The percentage aged 65+ and the percentage by cancer type in 2015 based on trend between 2010 and 2020 forecast.

3 Macmillan estimate of number of people diagnosed with cancer, based on incidence data from Office for National Statistics; Information Services Division (ISD) Scotland; Welsh Cancer Intelligence & Surveillance Unit; Northern Ireland Cancer Registry; and incidence projections from Mistry M, et al. 2011. Cancer incidence in the UK: Projections to the year 2030, Br J Cancer. 105: 1795–1803; and assuming 5% of people get two or more primary diagnoses of cancer as noted in Sasieni P.D, et al. What is the lifetime risk of developing cancer?: the effect of adjusting for multiple primaries. Br J Cancer. 2011. 105: 460 – 465.

4 Macmillan Cancer Support estimates cancer mortality trends to 2030 assuming trends from 2000 to 2010, continue at the same rate. 2000 to 2010 data are provided by Office for National Statistics (England and Wales); Scottish Cancer Registry & Northern Ireland Cancer Registry.
5 Macmillan broad estimate, of the number of people with a cancer diagnosis dying from cause other than cancer, using data on prevalence trends (see reference 1 & 2), people getting cancer (see reference 3) and people dying from cancer (see reference 4) along with all causes– mortality data from Office for National Statistics, General Registrar Office for Scotland, Northern Ireland Statistics and Research Agency. Estimate for 2030 has not been updated.

6 Average survival time is the median survival time since a cancer diagnosis when relative survival is at 50% and we interpret this as the time when half of the patients have survived (or half have died). Median survival time was calculated for people diagnosed in the periods 1971–72, 1990–91 and predicted for those diagnosed in 2007. Macmillan identified median survival times based on research by the Cancer Research UK Cancer Survival Group at the London School of Hygiene and Tropical Medicine. Incidence and mortality data for the survival analysis are originally sourced from the Office for National Statistics.
7 Predicted survival for these diagnosed in 2010–11. Cancer Research UK. 2014. Cancer Survival. 49.8% 10 year net survival index, all cancers combined, for adults (15–99 years) diagnosed with cancer in England and Wales during 2010–11.

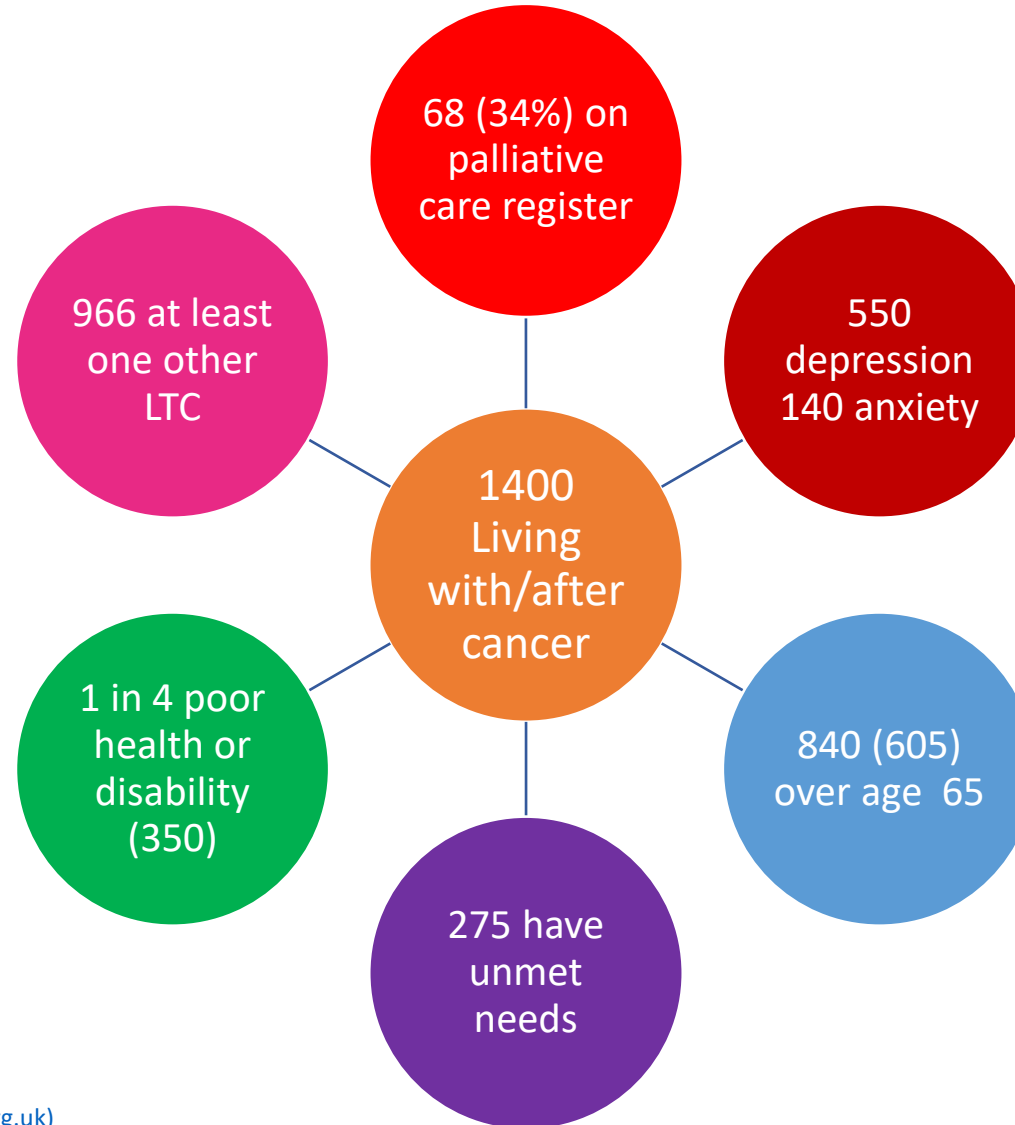# In A Primary Care Network of 40,000 patients

**1 or more LTC....**
**261** will have been prevented from working in their preferred occupation
**242** will visit a GP or HCP more than 10 times a year
**222** will find preforming ADLs very difficult

Greater needs than than the general population or people with a diagnosis of cancer and no other LTC (2)

**Poor health and disability...**
**245** chronic fatigue
**245** sexual difficulties
**168** mental health problems
**140** living with moderate to severe pain
**105** affected by urinary problems
**63** experiencing gastrointestinal problems
**46** experiencing lymphoedema

These problems may emerge months-years after treatment (1)

68 (34%) on palliative care register

966 at least one other LTC

550 depression
140 anxiety

1400 Living with/after cancer

1 in 4 poor health or disability (350)

840 (605) over age 65

275 have unmet needs

**Over 50% of those aged over 80**
will have moderate to severe functional disability affecting their QoL (3)

**Frailty...**
**80-89 years: 30%** at least are clinically frail
**90 years and above: 60%** at least are clinically frail (4)

Implications for referral, investigation, treatment and management for this group.

Slide Credit : Wessex Cancer Alliance .
References: 1.Cured but at what cost report (macmillan.org.uk)
2. Elliott J, Fallows A, Staetsky L, Smith PWF, Foster CL, Maher EJ, Corner J. The health and well-being of cancer survivors in the UK: findings from a population-based survey. 2011, Br J Cancer 105:S11-S20
3. Frailty: what's it all about? | British Geriatrics Society (bgs.org.uk)

Dyer S and Dewhurst 2020

Why GPNs need education on cancer . Primary Health Care.

DOI:10.7748/phc.2020.e1 566

Questions were designed to explore 3 specific areas;

1. Respondents understanding of the role of GPN in supporting people living with and beyond cancer
2. Confidence in delivering that role
3. Training (previous, future opportunities, barriers to access)

Headlines, 115 SWL GPN respondents

- **Over 70% of respondents had not received any training specific to cancer, of those who had, the majority related to screening services.**
- 55% have been working in general practice for > 10years
- 58% of respondents asked questions relating to cancer at least on a daily or weekly basis
- Only 11% currently complete CCRs, 13% were unaware of them.
- Over 70% were not confident in completing a CCR

# Cancer in the Community Education Project

Successful HEE funded SWL Pilot ran 2019 for community

Nurses

Successful pilot success and HEE funded to run London-wide in 2020 -2023

Community nurses, GPNs, and small number of community AHPs.

Increased competence and confidence demonstrated through evaluation.

Cancer COP developed out of this work .

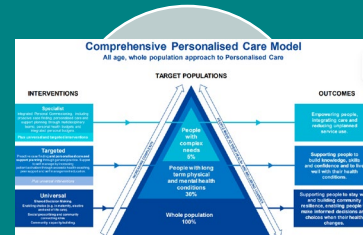# Touchpoints - Community and Primary Care Nursing and Cancer

Programme covers whole cancer pathway and suitable for range of community-based nurses and GPNs

Prevention, cancer screening, early diagnosis

Support during treatment- post surgery, care of IV lines, administration of medication etc

living with cancer, living with COTs, rehabilitation, recurrence , frailty and complexity with MDT

End of life care- shared decision making , ACP, and enabling preferred place of death.

**Community Nursing-Including Adult, SPQ DN, Learning disability, Mental Health Specialist Nurse & GPNs, ANPs**

# Cancer Community of Practice

# The COP

**The London Cancer Community of Practice (COP) launched in Feb 2023**

Developed as an output from the London Cancer in the Community Education programme

Brings together nurses and AHPs in primary and community care , with specialist cancer nurses and AHPs, to improve knowledge, and develop practice and influence change

Creates opportunities to learn and collaborate across organisational boundaries to improve patient care and experience
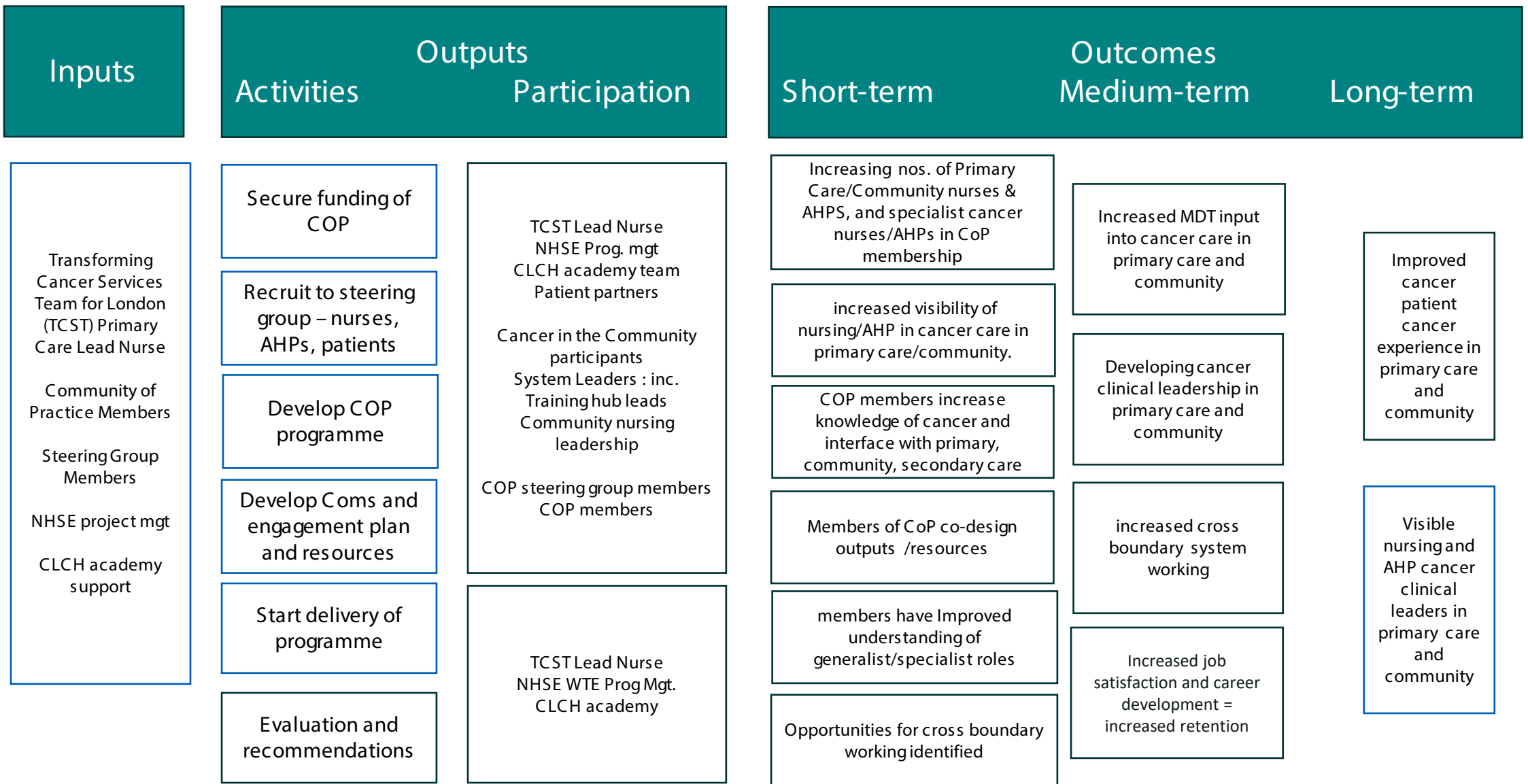
Multi-professional cross sector steering group in place, with patient partner involvement.

## Co-design with steering group

- 10 events per in year one : 6 webinars, plus 4 in-person events

- Membership: Former CiC programme delegates & London GPN CoP members, primary and community nurses/AHPs, CNS' and AHPs in specialist cancer services

| Inputs | Outputs | | Outcomes | | |
|---|---|---|---|---|---|
| | Activities | Participation | Short-term | Medium-term | Long-term |

| Inputs | Activities | Participation | Short-term | Medium-term | Long-term |
|---|---|---|---|---|---|
| Transforming Cancer Services Team for London (TCST) Primary Care Lead Nurse<br><br>Community of Practice Members<br><br>Steering Group Members<br><br>NHSE project mgt<br><br>CLCH academy support | Secure funding of COP<br><br>Recruit to steering group – nurses, AHPs, patients<br><br>Develop COP programme<br><br>Develop Coms and engagement plan and resources<br><br>Start delivery of programme<br><br>Evaluation and recommendations | TCST Lead Nurse<br>NHSE Prog. mgt<br>CLCH academy team<br>Patient partners<br><br>Cancer in the Community participants<br>System Leaders : inc. Training hub leads<br>Community nursing leadership<br><br>COP steering group members<br>COP members<br><br><br>TCST Lead Nurse<br>NHSE WTE Prog Mgt.<br>CLCH academy | Increasing nos. of Primary Care/Community nurses & AHPS, and specialist cancer nurses/AHPs in CoP membership<br><br>increased visibility of nursing/AHP in cancer care in primary care/community.<br><br>COP members increase knowledge of cancer and interface with primary, community, secondary care<br><br>Members of CoP co-design outputs /resources<br><br>members have Improved understanding of generalist/specialist roles<br><br>Opportunities for cross boundary working identified | Increased MDT input into cancer care in primary care and community<br><br>Developing cancer clinical leadership in primary care and community<br><br>increased cross boundary system working<br><br>Increased job satisfaction and career development = increased retention | Improved cancer patient cancer experience in primary care and community<br><br>Visible nursing and AHP cancer clinical leaders in primary care and community |

| Assumptions: TCST role , NHSE prog mgt and CLCH academy support & engagement in CoP | External Factors: system & workforce capacity , funding for programmes |
|---|---|

# Collaborations

**Face to face sessions enable members to work with others in their local system,**

**Organisational collaborations- key to success and sustainability with mutual benefits**
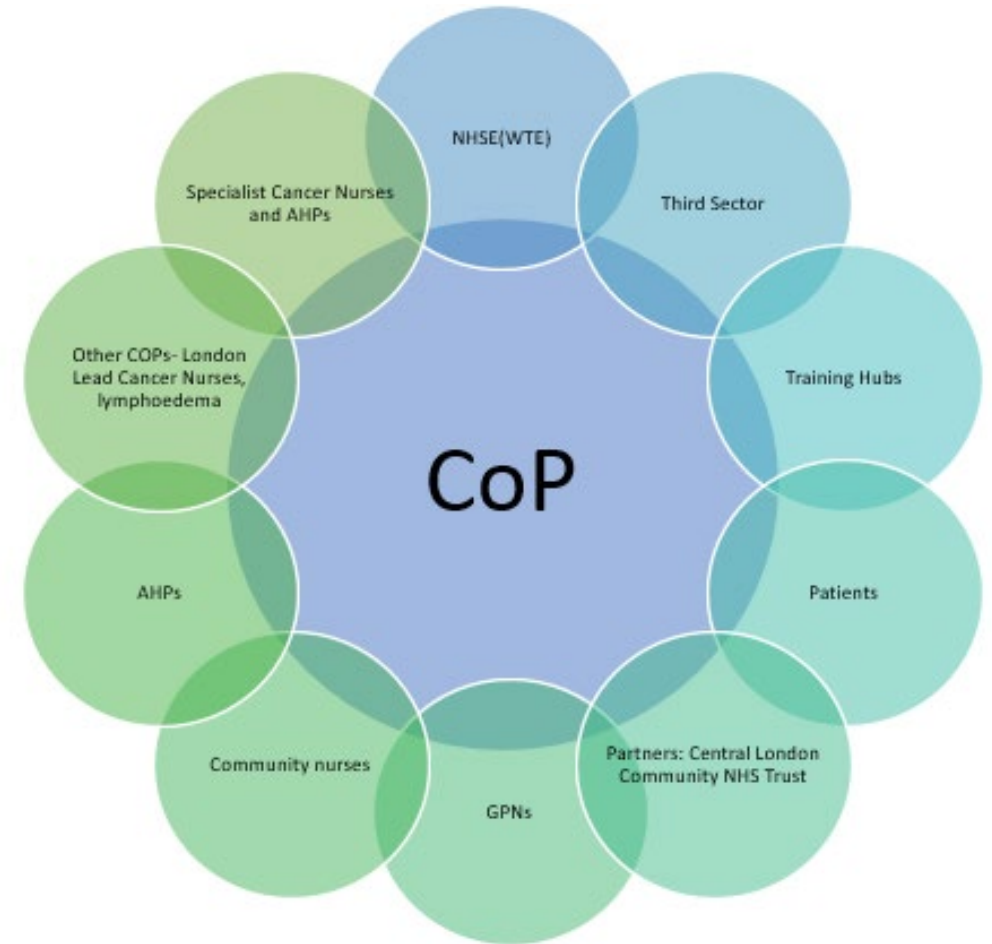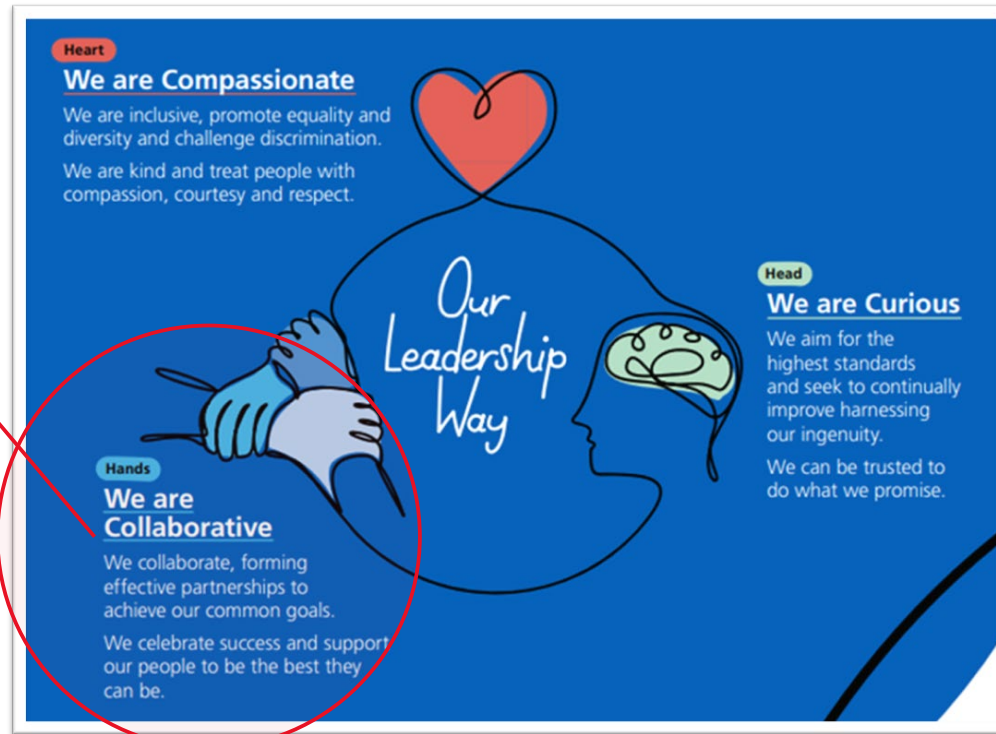
# Quality improvement/World cafe

The World Cafe is a method which makes use of an informal cafe setting for participants to explore an issue by discussing it in small table groups. Discussion is held in multiple rounds of 20-30 minutes, with the cafe ambiance intended to allow for more relaxed and open conversations to take place.

# Shadowing opportunities/Interprofessional learning

*Information sharing and communication between primary and secondary care must improve to meet the increasing demand for support for people living with and beyond cancer. Delivering integrated pathways between primary and secondary care will yield improvements in patient outcomes and health economic costs (Collaço, N et al, 2024).*



Through the COP we plan to put together a small working group to look at what shadowing opportunities there may be across London boroughs and to carry out a scoping review. The aim of the review would be to identify how interprofessional learning is defined and the methodology underlying the implementation of such an approach.

The Wheel of Integrated System Change
Quality Improvement, Leadership and Learning Health Systems
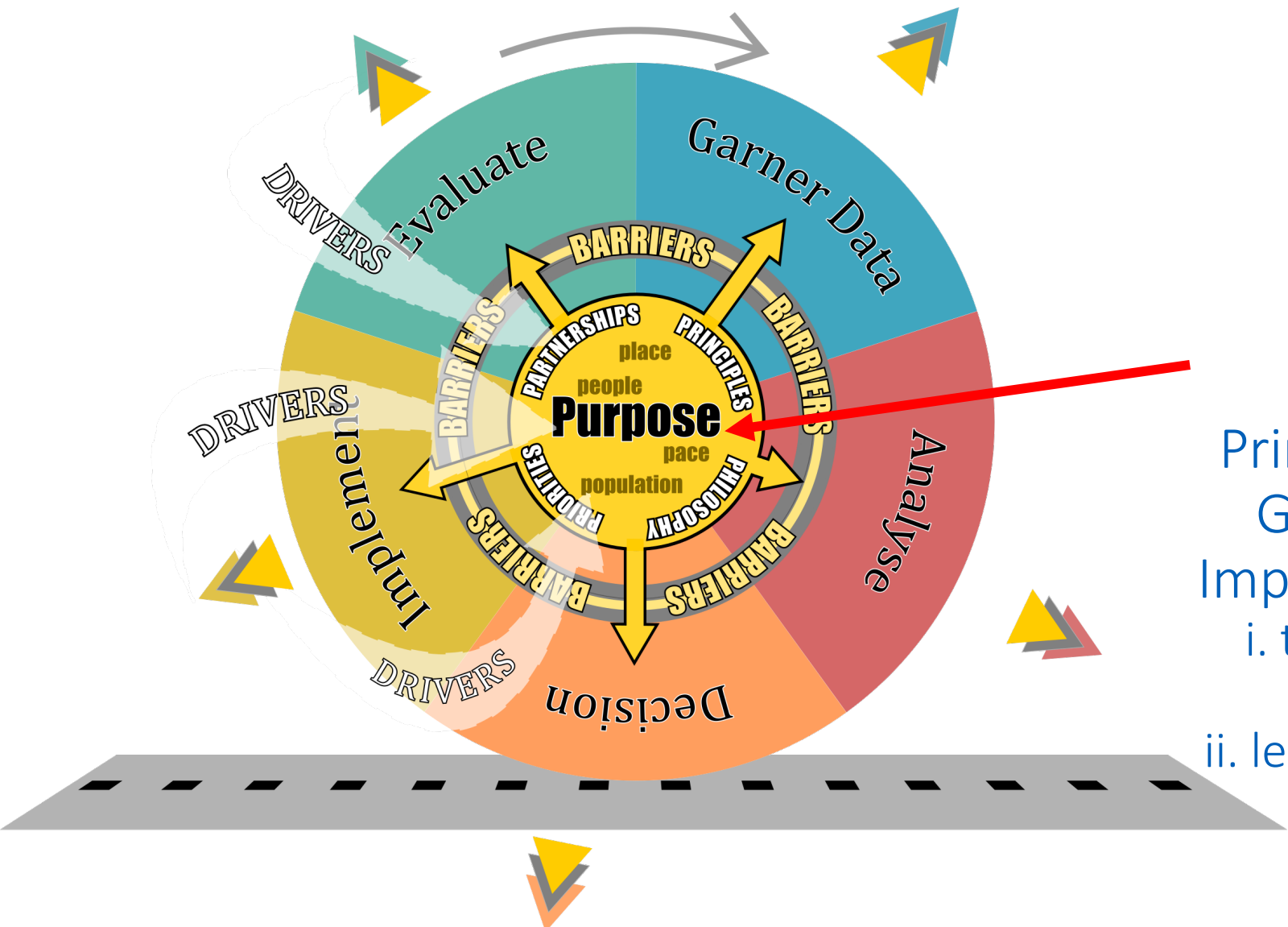
Primary Care and Cancer CoP & NT GMSA have a shared purpose = Improve Patient care and experience
i. to improve nurse/ AHP knowledge & practice
ii. learn and collaborate across boundaries

Evaluation Findings

# Membership

- Cancer CoP engagement has grown significantly in 2023/24
- Between 30 – 40 CoP members attend in-person events
- Average 119 registrations at webinars
- 186 COP members
- Range of job roles in both membership and steering group

**What is your Job role?**

- Advanced Clinical
- Clinical Nurse Spec
- Community Nurs
- General Practi
- Other

14%
5%
16%
38%
27%

**, are you based in?**

Charity 4%
Community 14%
Secondary care 18%
Primary care 64%
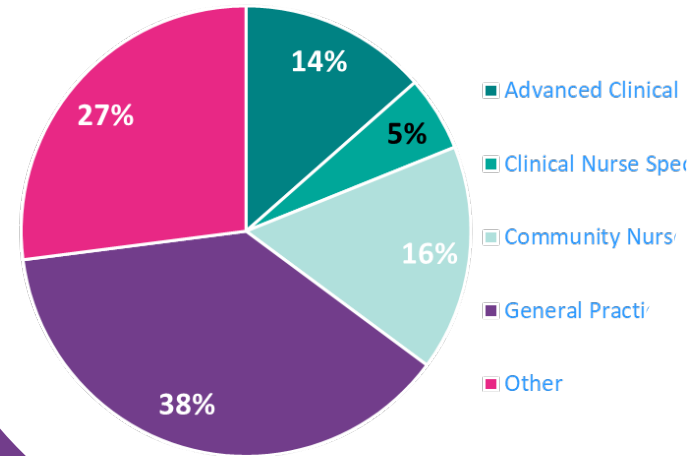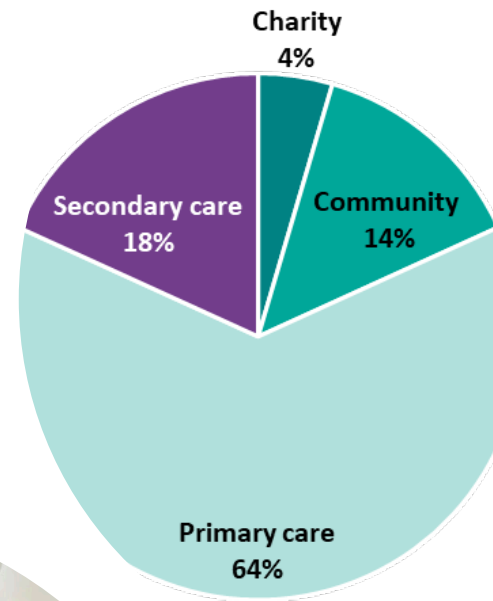
# Learning and user engagement

Events were evaluated using a mixed method survey of attendees after the event. Based on 6 webinars and 3 face to face events

- Webinar/In-person average ratings: 4.63/5

- Attendees positive about making changes to practice

Webinars co-produced/ delivered with COP members

**What will you take away from today ?**

*"Consciously implement techniques into patient care"*

*"Sharing knowledge with colleagues at clinical meetings"*

*"Review training opportunities for my team"*

*"Research leadership development courses"*

*"Implement ideas into service analysis"*

*"Attend more events to network with colleagues"*

# Evaluation themes

## Supporting innovation

"*Day full of innovation-enjoyed the networking. Now the ideas are flooding in*"

## Interactive and safe environment

"*Great effort to run an interactive morning. I think people felt able to participate without the scariness of public speaking*"

## Connecting professionals building & Community

" *I was captivated with the content of the day and the passion of everyone wanting to make a difference for patients*"

## Changing Practice ( self and others)

"*I'll take the learning on cancer and delirium back to my team* "

"*I have seen examples of how colleagues have taken behaviours from webinars/events and actioned them in their own work.*"

| Inputs | Outputs | | Outcomes | | |
| | Activities | Participation | Short-term | Medium-term | Long-term |

**Inputs**

Transforming Cancer Services Team for London (TCST) Primary Care Lead Nurse

Community of Practice Members

Steering Group Members

NHSE project mgt

CLCH academy support

**Activities**

Secure funding of COP

Recruit to steering group – nurses, AHPs, patients

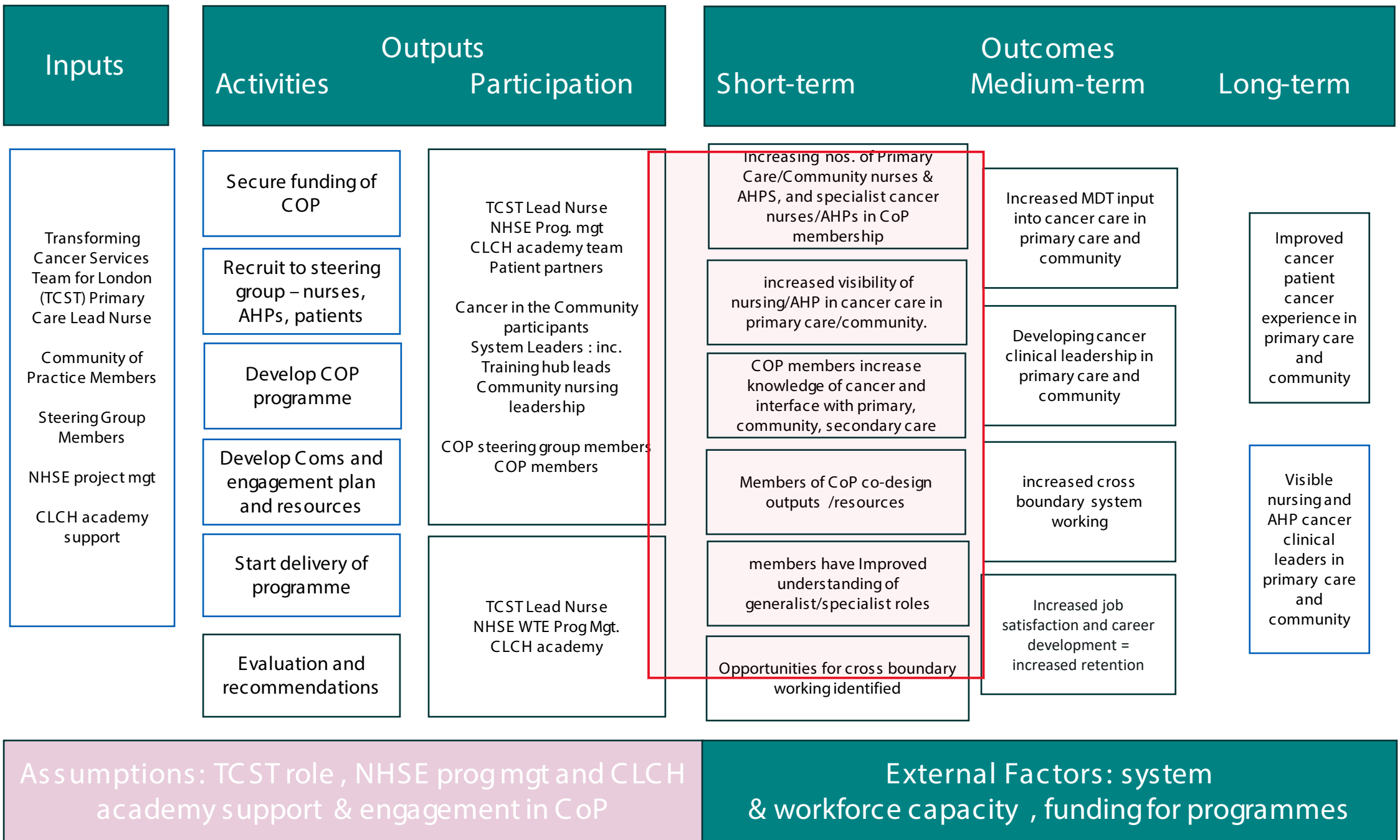Develop COP programme

Develop Coms and engagement plan and resources

Start delivery of programme

Evaluation and recommendations

**Participation**

TCST Lead Nurse
NHSE Prog. mgt
CLCH academy team
Patient partners

Cancer in the Community participants
System Leaders : inc. Training hub leads
Community nursing leadership

COP steering group members
COP members

TCST Lead Nurse
NHSE WTE Prog Mgt.
CLCH academy

**Short-term**

Increasing nos. of Primary Care/Community nurses & AHPS, and specialist cancer nurses/AHPs in CoP membership

increased visibility of nursing/AHP in cancer care in primary care/community.

COP members increase knowledge of cancer and interface with primary, community, secondary care

Members of CoP co-design outputs /resources

members have Improved understanding of generalist/specialist roles

Opportunities for cross boundary working identified

**Medium-term**

Increased MDT input into cancer care in primary care and community

Developing cancer clinical leadership in primary care and community

increased cross boundary system working

Increased job satisfaction and career development = increased retention

**Long-term**

Improved cancer patient cancer experience in primary care and community

Visible nursing and AHP cancer clinical leaders in primary care and community

**Assumptions: TCST role , NHSE prog mgt and CLCH academy support & engagement in CoP**

**External Factors: system & workforce capacity , funding for programmes**

conclusion

# Next Steps - plan for 2024/5

## Aim to move towards medium term goals

- Focus on sustainability in context of uncertain funding environment

- Deliver a series of events for 2024- member led.

- Create links with other communities of practice e.g. Lead cancer nurse forum, Lymphedema CoP

- Develop shadowing opportunities across primary/community and secondary care

- Conferences- submit abstract to Multinational Association of Supportive Care in Cancer

- Publication

- Collaboration with other UK regions



**Picture: Cancer CoP Poster Presentation**
UKONS Conference (17-18 Nov 2023**)**

# Any questions for us ?

**Transformation Partners**
**in Health and Care**

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