



European Cancer
Patient Coalition



ECPC Annual General Meeting 2019:

Unmet needs of cancer patients and their families are being met by Volunteer-led community-based cancer support centre

But not everyone can access this support

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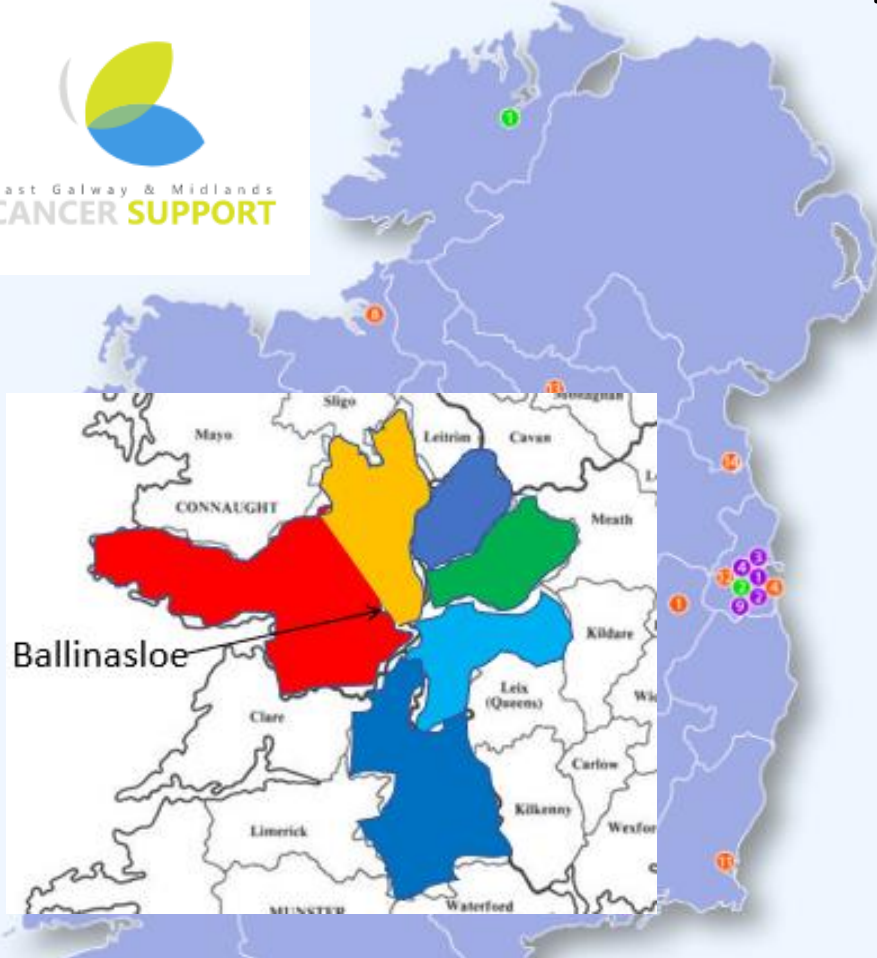




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Background

Regional Cancer Services



Designated Cancer Centres

- 1 Mater Misericordiae Hospital
- 2 St. Vincent's University Hospital
- 3 Beaumont Hospital
- 4 St. James's Hospital
- 5 Cork University Hospital
- 6 University Hospital Waterford
- 7 University Hospital Limerick
- 8 University Hospital Galway
- 9 Our Lady's Children's Hospital Crumlin

Centres with full-time Medical Oncology/ Haematology Consultants

- 10 Letterkenny University Hospital
- 11 Tallaght Hospital
- 12 Midlands Regional Hospital, Tullamore

Centres with nurse-led units and visiting Medical Oncologist/Haematologist

- 13 Naas General Hospital
- 14 Mercy University Hospital, Cork
- 15 South Infirmity Victoria University Hospital
- 16 St. Luke's Hospital, Dublin
- 17 Kerry University Hospital
- 18 South Tipperary General Hospital, Clonmel
- 19 Mayo University Hospital
- 20 Sligo University Hospital
- 21 Portiuncula Hospital, Ballinasloe
- 22 St. Luke's General Hospital, Kilkenny
- 23 Wexford General Hospital

NATIONAL CANCER STRATEGY

2017 - 2026

~40 groups/centres

Volunteer Services

2 of the designated cancer centres have a dedicated psycho-oncology service, and one of these is part-time. (pg 93)



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Objectives



- To investigate the unmet needs of cancer patients attending a volunteer-led cancer support service
- To understand the supportive interventions needed by cancer patients
- To perform a Budgetary Impact Analysis
- To use findings to assist development of services locally and nationally

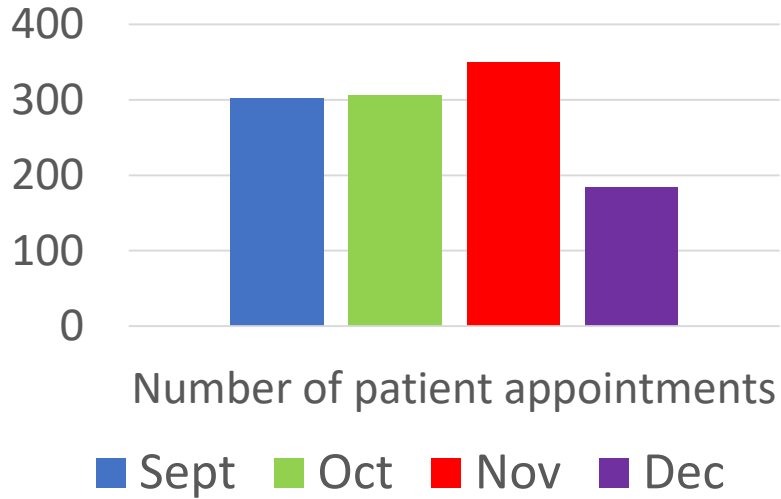
Partnerships: Dr Aileen Murphy, Health Economist, UCC

Professor Josephine Hegarty, Prof of Nursing, UCC

Dr Conan Donnelly, Research Manager, National Cancer Registry, Ireland

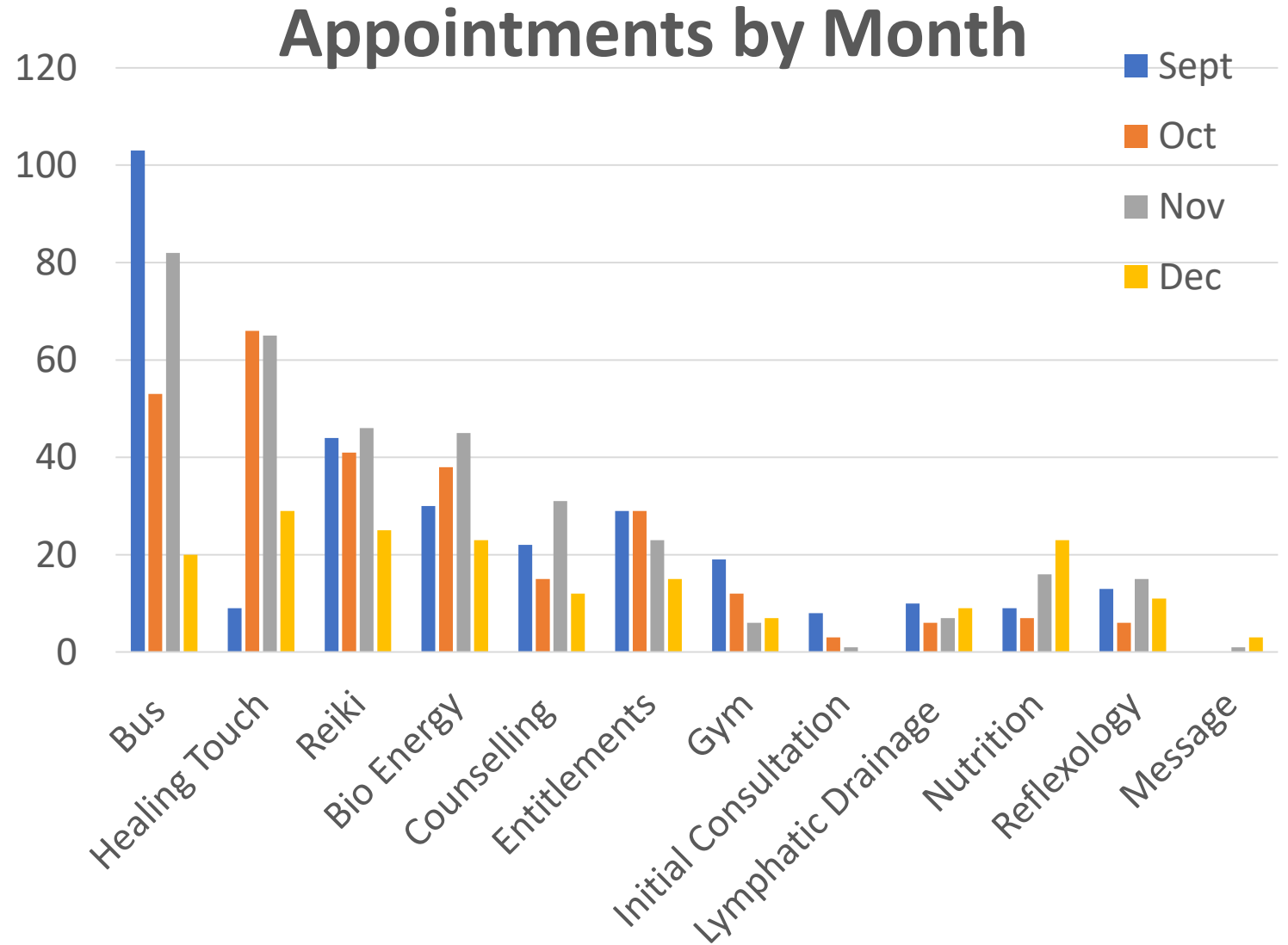


Outcomes – Extent of engagement



N=3173 Patient contacts (Sept-Dec)

- N=1142 appointments
- N=1973 drop ins/lunch
- N=58 phone calls*



*Not complete



Outcomes

Changes since using the support centre?

- Cross-sectional survey sent to 225 patients
- N=113 responders (51%)

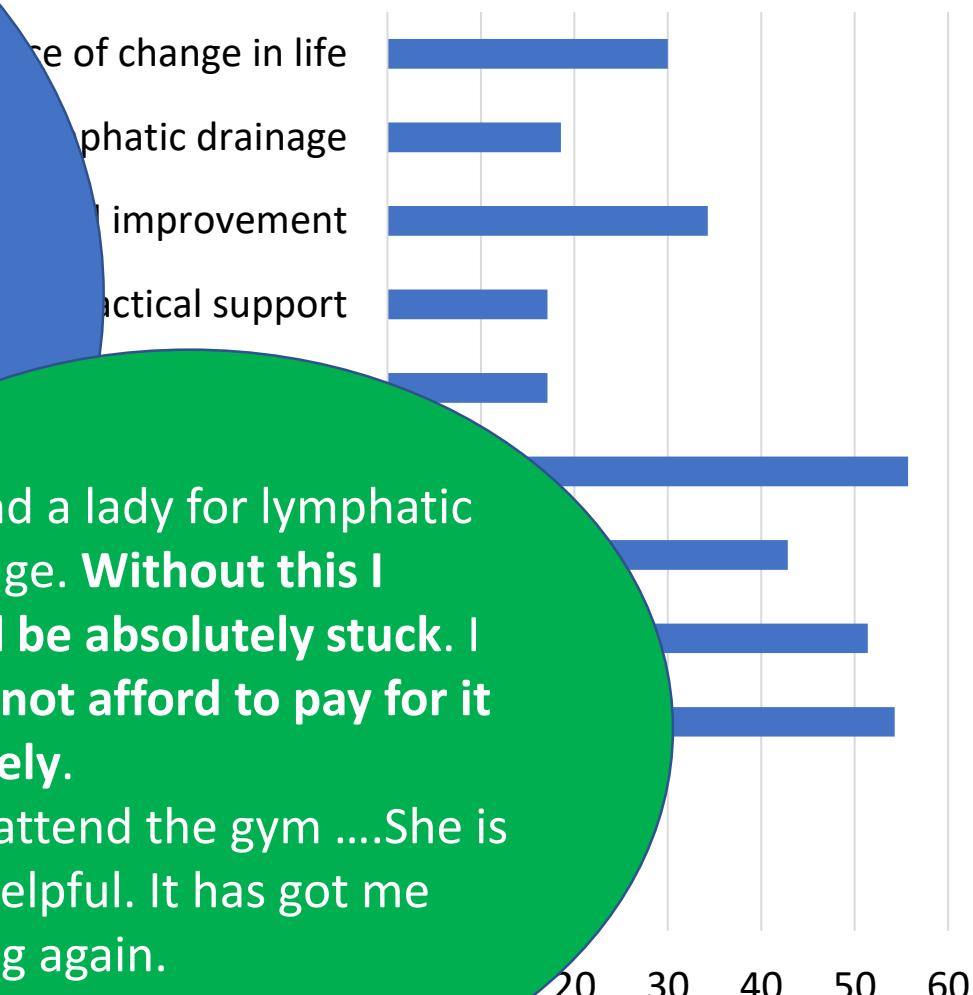
Unmet needs (%)



because I'm from [town name] I was sometimes **too tired** to drive down and because work was not paying me when I was on treatment I had to factor in the **petrol expense** into my sickness benefit and some weeks I could not afford to travel, cancer can be very expensive when you are not working and trying to keep your every day bills paid so awful time,

I attend a lady for lymphatic drainage. **Without this I would be absolutely stuck. I could not afford to pay for it privately.** I also attend the gymShe is very helpful. It has got me moving again.

%Yes





Lessons learned

- Recording of services supplied in voluntary services is vital as a quality measure
- Unmet needs are common among cancer survivors using the centre
- Cancer survivors report that many interventions are necessary to support them (practical, psychological, spiritual, physical, social)
- Often multiple supports required - Different at different points in survivorship
- Community/peer-support not for everyone (do not want to talk about cancer/participate in groups)
- Supports are not accessible to everyone (Barriers: transport/finance/work and childcare; awareness of services by patients)
- Evaluation assists in service development