How can we better co-ordinate care for people living with and beyond cancer who have complex needs (with one or more health problems?)

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Background: By 2030, four million people in the UK will be living with the long-term consequences of cancer, but currently there is very little research on the problems they face and how these can be tackled. To determine priorities for research that will help people live better with and beyond cancer, NCRI collaborated with the James Lind Alliance on a Priority Setting Partnership to identify the top cancer research priorities. In 2019, National Cancer Research Institute published the top 10 research priorities of which better care for those with complex needs was ranked third.

1.8 million people are living with one or more other potentially serious long-term health conditions in addition to cancer – more than two in three (70%) of those with cancer. Almost half (47%) have two or more conditions as well as cancer, and more than one in four (29%) have three or more conditions as well as cancer. The top five most common long-term conditions for people with cancer are High blood pressure (hypertension) (32%) , Obesity – 31%, Mental health problems – 21%, Chronic heart disease – 19% and Chronic kidney disease – 17%.

Cancer patients are surviving for longer periods with co-morbid conditions, which may be coincidental, sequelae of cancer, or treatment related side effects. The management of multiple morbidities creates significant pressure on the NHS, largely because of a service delivery model that generally separates specialist and generalist services. Caring for a cancer patient with multi-morbidities is severely challenging owing to coordination of care, multiple personal needs and appointments, polypharmacy and the limited availability of support and clinical guidance. Despite this, there is limited empirical evidence and clinical guidelines regarding this large disparate group, and those that do exist have a questionable evidence base, do not offer solutions, and lack evidence of meaningful involvement of end users in their evidence base.

Aims: This project aims to develop a cancer action plan that is responsive to the needs of people living with and beyond cancer who have complex needs. Through partnership working with patients, carers and health care professionals the action plan will identify priorities for research and practice and robust strategies for service improvement delivery.

We will do this by:

1. Synthesising and appraising the literature regarding unmet supportive care needs of

people affected by cancer with one or more conditions.

2. Conducting prevalence calculations in partnership with the Northern Ireland cancer registry to determine the nature and prevalence of multiple conditions in cancer patients in Northern Ireland .

3. Giving depth and breadth to the issues identified in objective 1+2 by conducting qualitative

Interviews with patients and their informal carers affected by cancer and complex needs across the NI.

4.Building on objective 1,2 and 3 by ascertaining depth and breadth to the issues faced by

Patients by conducting qualitative interviews with healthcare professionals and

Relevant stakeholders in NI.

5. Using objective 1-4 to develop priorities and strategies for research and practice with patients and their families affected by cancer complex needs through a multi-stakeholder workshop.