Scottish
Cancer Network

NHS
SCOTLAND

BREAST CANCER SUPPORTIVE CARE

EDUCATIONAL SYMPOSIUM

FEAR OF RECURRENCE & PROVISION OF PSYCHOLOGICAL SUPPORT & THERAPY

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NHS SCOTLAND

BREAST CANCER SUPPORTIVE CARE
EDUCATIONAL SYMPOSIUM

Fear of Recurrence (FCR)

Definition:

…"the fear, worry or concern relating to the possibility that cancer could come back or progress in the same place or in a different part of the body"

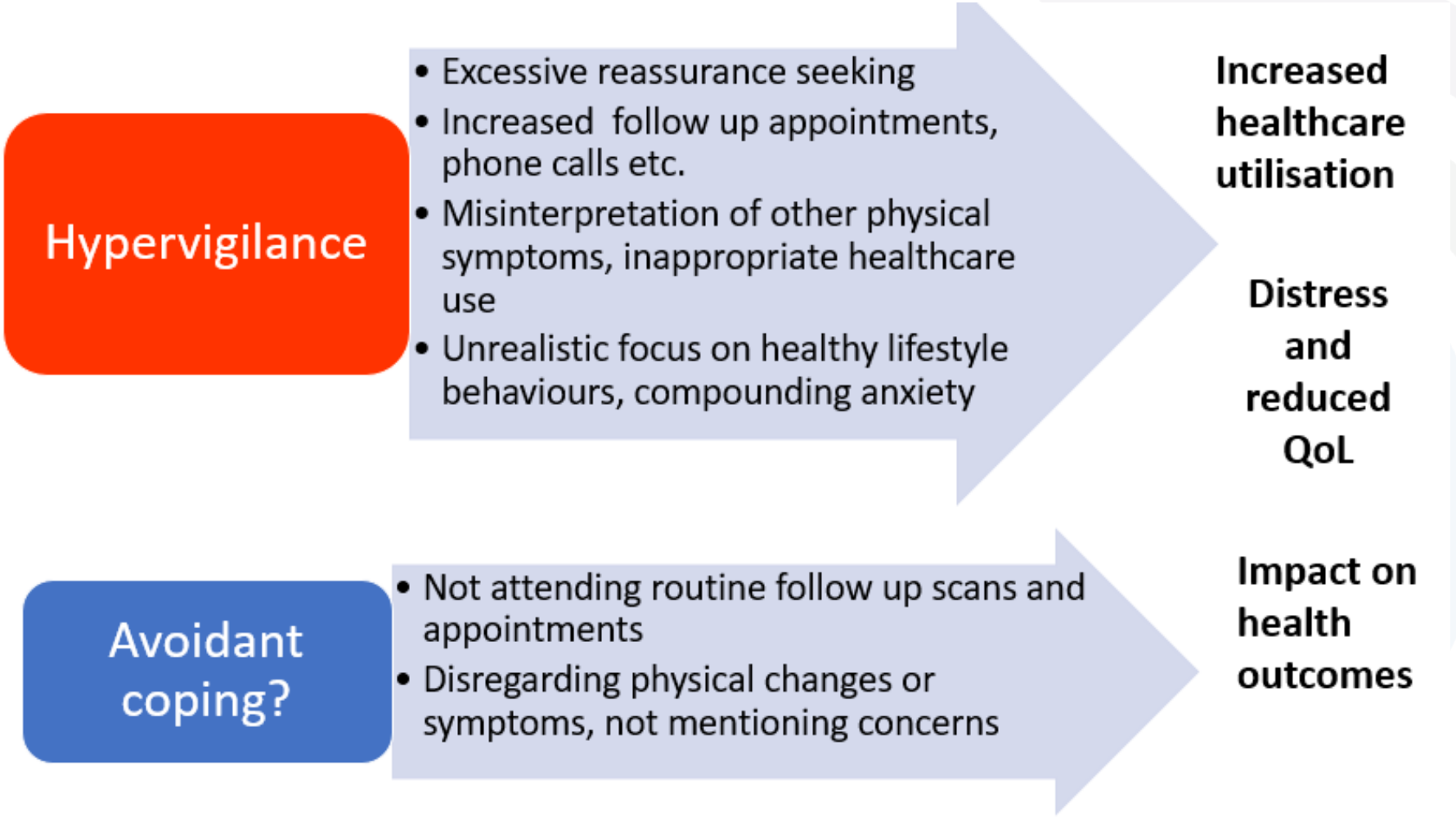
Unmet need

Measurement of FCR can be challenging

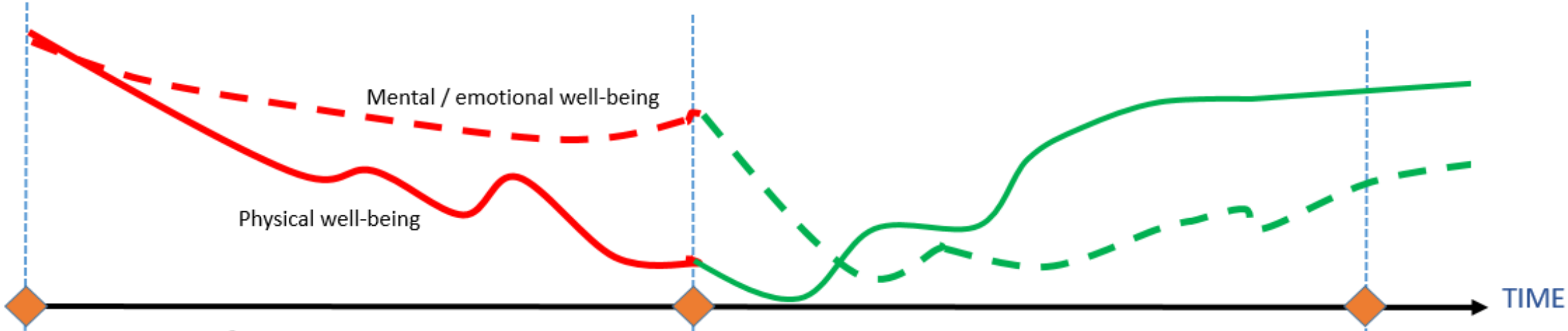
Prevalence rates range widely recent large meta- analysis reported 59% experience moderate FCR and 19% high FCR

- Butow, P. N et al. *Psycho-oncology* (pp. 625–629). Oxford University Press.
- Luigjes-Huizer et al 2022 What is the prevalence of fear of cancer recurrence in cancer survivors and patients? A systematic review and individual participant data meta-analysis. Psycho-oncology https://doi.org/10.1002/pon.5921

What is the impact of FCR?



What People Tell Us



Management of cancer diagnosis

Treatment.....

Patient

Surgery

Tests

Chemo

Life managed by:
- Treatments
- Emotions
- Insecurity
- Hospital visits
- Waiting

Completion of primary treatment

Tests

Surgery

Radiotherapy

Transition

Lack of information
Lack of support
Loss of libido
Anger, sadness, Fear, grief

Chemo brain

Worries

Early Menopause

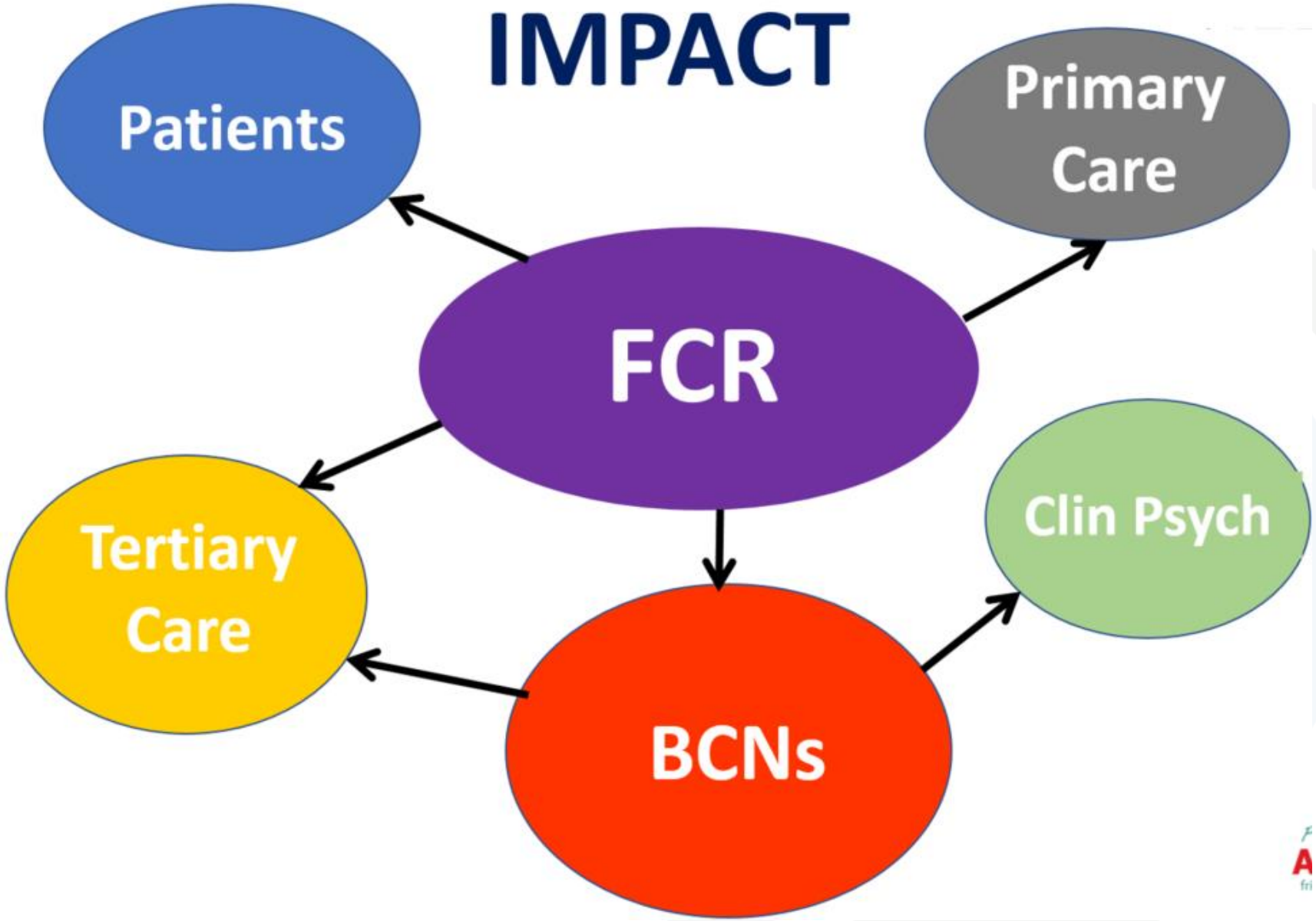
Hormone Treatment

Who am I?
What do I really want?
How can I cope?
What about work?
What's important now?
What are my priorities?

New Normal

HOSPITAL BASED TREATMENT

POST TREATMENT TRANSITION


IMPACT
Patients
Primary Care
FCR
Tertiary Care
Clin Psych
BCNs

ICANBE Team

University of Aberdeen

- Prof Sara MacLennan- Lead of ICANTREAT group, UoA
- Solveiga Zibaite- post doc Research Fellow, UoA

NHS Grampian

- Dr Helen Moffat and Dr Vera Elders- Clinical Psychologists
- Miss Beatrix Elsberger- Consultant Breast Surgeon

Friends of ANCHOR
friendsofanchor.org

Project Aims

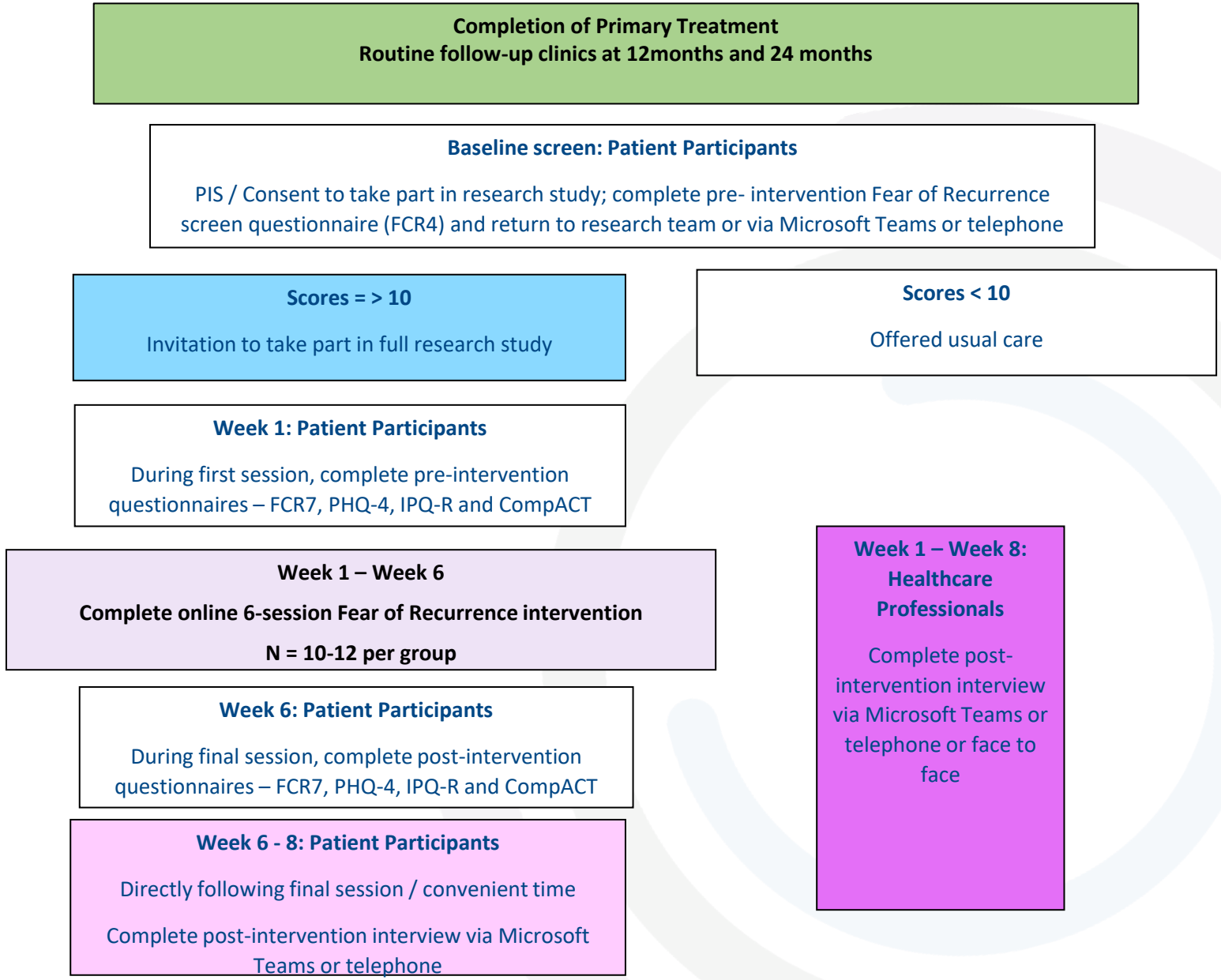
Aims:

- **Develop a new service for Fear of Cancer Recurrence (FCR) in the North-East of Scotland**
- **Conduct a small-scale evaluation of this service (those delivering, those referring and those receiving this psychological therapy) and build case for further evaluation and development**

Objectives:

- **Evaluation of the proposed online group FCR intervention for women diagnosed with and treated for breast cancer within the North-East of Scotland**
- **Develop recommendations for a Fear of Cancer Recurrence psychological pathway**

Research Design – Multi-Methods:



Fear of Cancer Recurrence scale (FCR7) – selected following consultation with clinical team and patients

FCR7 Items†

Please answer the following questions by placing a tick in any of the boxes for each of the question.

You do not have to answer these questions if you do not wish. We will anonymise your information.

Please hand this scale to your specialist. Thank you!

	Not at all 1	A little 2
Q1: I am afraid that my cancer may recur	☐	☐
Q2: I am worried or anxious about the possibility of cancer recurrence	☐	☐
Q3: How often have you worried about the possibility of getting cancer again	☐	☐
Q4: I get waves of strong feelings about the cancer coming back	☐	☐
Q5: I think about the cancer returning when I didn't mean to	☐	☐
Q6: I examine myself to see if I have physical signs of cancer	☐	☐

FCR4

	Not at all 0	1	2	3
Q7: To what extent does worry about getting cancer again spill over or intrude on your thoughts and activities				

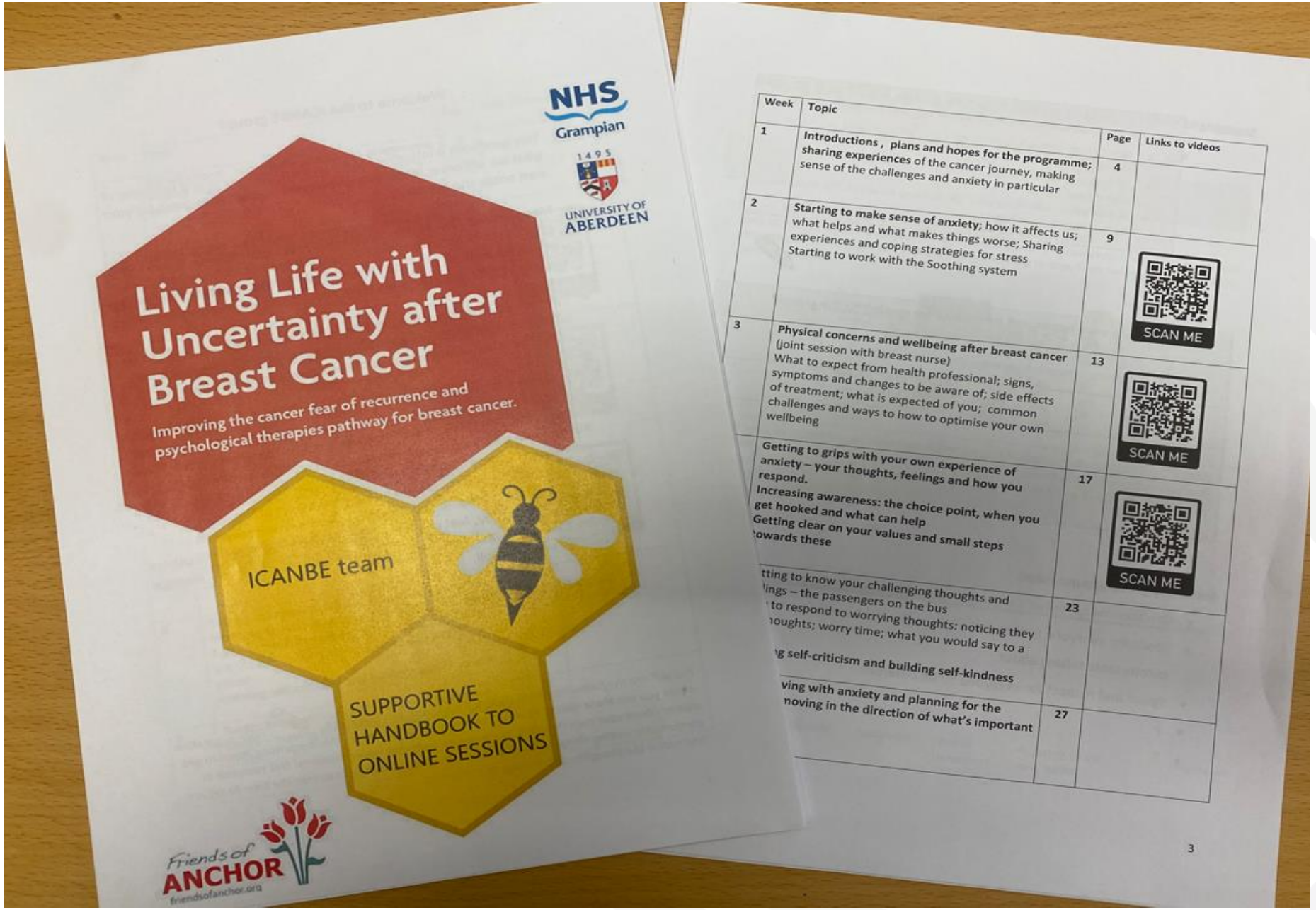
The Intervention

- Online group setting delivering an Acceptance and Commitment Therapy based intervention over 6x 90 minute sessions
- Handbook with links to videos containing most of psycho-educational content

Near Me

attendanywhere

- Engagement and connections; normalising post-treatment challenges
- Psycho-education; giving anxiety management and coping strategies
- Physical concerns - delivered with CNS
- Support to move towards valued living and identify goals
- Cognitive and practical strategies including self-compassion
- Consolidation, anticipation of future challenges


NHS
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UNIVERSITY OF
ABERDEEN
Living Life with Uncertainty after Breast Cancer
Improving the cancer fear of recurrence and psychological therapies pathway for breast cancer.
ICANBE team
SUPPORTIVE HANDBOOK TO ONLINE SESSIONS
Friends of ANCHOR
friendsofanchor.org
Week
Topic
Page
Links to videos
1
Introductions , plans and hopes for the programme; sharing experiences of the cancer journey, making sense of the challenges and anxiety in particular
4
2
Starting to make sense of anxiety; how it affects us; what helps and what makes things worse; Sharing experiences and coping strategies for stress
Starting to work with the Soothing system
9
SCAN ME
3
Physical concerns and wellbeing after breast cancer (joint session with breast nurse)
What to expect from health professional; signs, symptoms and changes to be aware of; side effects of treatment; what is expected of you; common challenges and ways to how to optimise your own wellbeing
13
SCAN ME
Getting to grips with your own experience of anxiety – your thoughts, feelings and how you respond.
Increasing awareness: the choice point, when you get hooked and what can help
Getting clear on your values and small steps
owards these
17
SCAN ME
tting to know your challenging thoughts and lings – the passengers on the bus
to respond to worrying thoughts: noticing they oughts; worry time; what you would say to a
g self-criticism and building self-kindness
23
ving with anxiety and planning for the noving in the direction of what's important
27
3

Fear of Cancer Recurrence (FCR7 Score)

PRE-COURSE FCR7 SCORE	POST-COURSE FCR7 SCORE	CHANGE
29	26	-3
34	21	-13
39	33	-6
28	27	-1
30	21	-9
32	31	-1
40	18	-22
23	18	-5
31	27	-4
31	28	-3
30	25	-5

Qualitative Results: Acceptability for Participants

'it can take just a very, very small thing, which could possibly be quite insignificant, like 'oh the GP looked at me the wrong way, he knows something that he isn't telling me'. That just pushes me over again to all the, the negative emotions that come with a diagnosis like this…'

'One of the wonderful things I found with being a part of this group is that I realized that I'm not abnormal. Because I felt that all the emotions and everything I was feeling, it was just me and that I was being very stupid and immature and overemotional. But then having been part of the group, I realized that it's just quite normal'

'…you've given us the terminology and the framework of what we've been going through. And I think that is something, there's something tangible. We've got a handbook, we can understand what it is we're going through. And I think that's been really important, having that specific course.'

'… I think I felt a little bit of apprehension all the way through but because of the situation I thought to myself, well just say it Rose. Just put it out there, which I did…'

Acceptability for Health Professionals:

'I think fear of recurrence would come with majority of all our ladies. I would say there's very little patients that I would think wouldn't be worried about it coming back. It's such a big thing'

'…I think it would be beneficial, and I think it probably would benefit us as well because it may then reduce the amount of regular calls from people that were worrying if things were addressed and identified and made them a bit more confident in what to be looking out for…'

'…if it's short, it's snappy, you wouldn't mind saying…"How do you feel if it's on a scale of zero to ten, how do you feel right now?" And then you maybe feel more comfortable to say, well actually, your score is quite high here, we do have this group available if you would be interested…'

'…that type of people really need to go on the course who don't think they need to and just give them a leaflet, they wouldn't apply for it. It's trying to catch that type of lady…'

Key findings

- Differences in level of FCR depending on age, route to diagnosis, individual personality
- For Patients: Differences about how and when to contact breast care nurses for support expressed by women; perception of team being busy but excellent
- For HCPs: Differences about when and how recurrence is best introduced in the journey; who, when and how should raise this; BCN fear of upsetting women
- Intervention felt to be needed, useful and well-delivered; materials and mode of delivery (online) and group size acceptable; women confident to engage; HCPs happy to screen & refer
- Differences in group composition e.g. breast only or all cancers expressed by women
- Sense of group – organic social support, community (e.g. WeCanBe) very important

Recommendations for Breast Care Services

Service Needs: Policy (Pathway and FoR guidelines), Staffing and Training Resources

Screening and Tools:
- 1 yr follow-up
- 2 yr follow – up
- Contact with HCPs

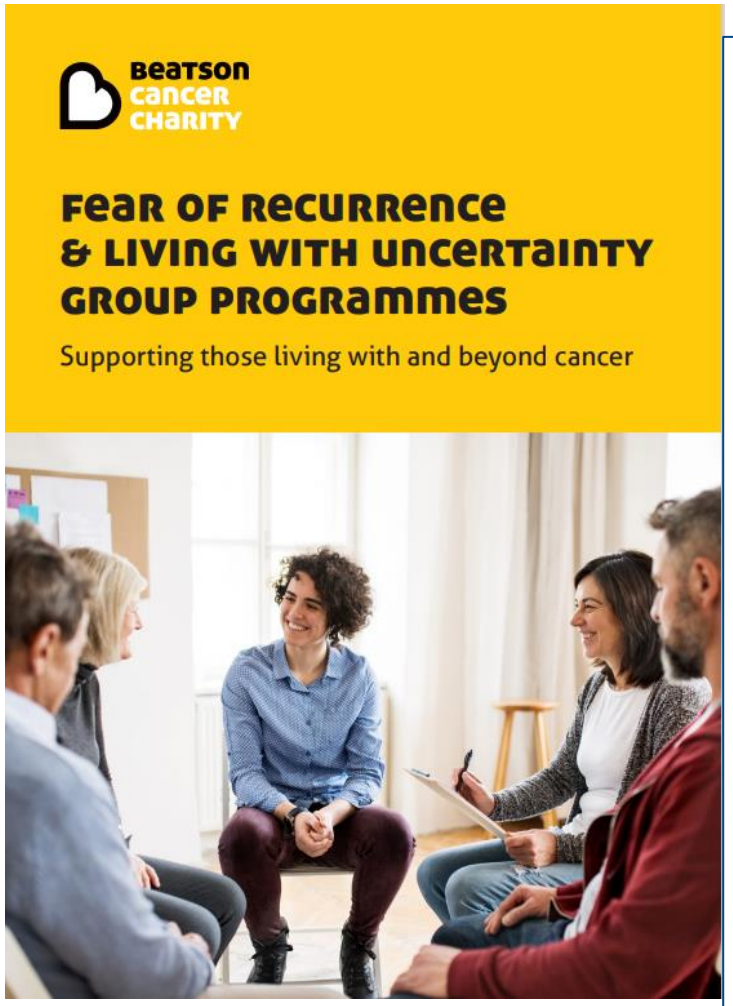
Information Needs Triage:
- Written Information
- FoR Course Materials, Web Platform and Handbook
- FoR Course place in group intervention

Delivery:
- Clinical Psychologists
- Breast Care Nurses
- Expert Peer Support

Training: Communication around Risk of Recurrence and Fear of Recurrence; Breast Care Pathway and Roles and Responsibilities

Roles: Who discusses Risk of Recurrence and signs / symptoms; when does this happen in the Breast Care Pathway?

Groups Delivered by the Beatson Cancer Charity



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RESEARCH

Real-world evaluation of an acceptance and commitment therapy–based group programme for breast cancer survivors with fear of cancer recurrence

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Abstract

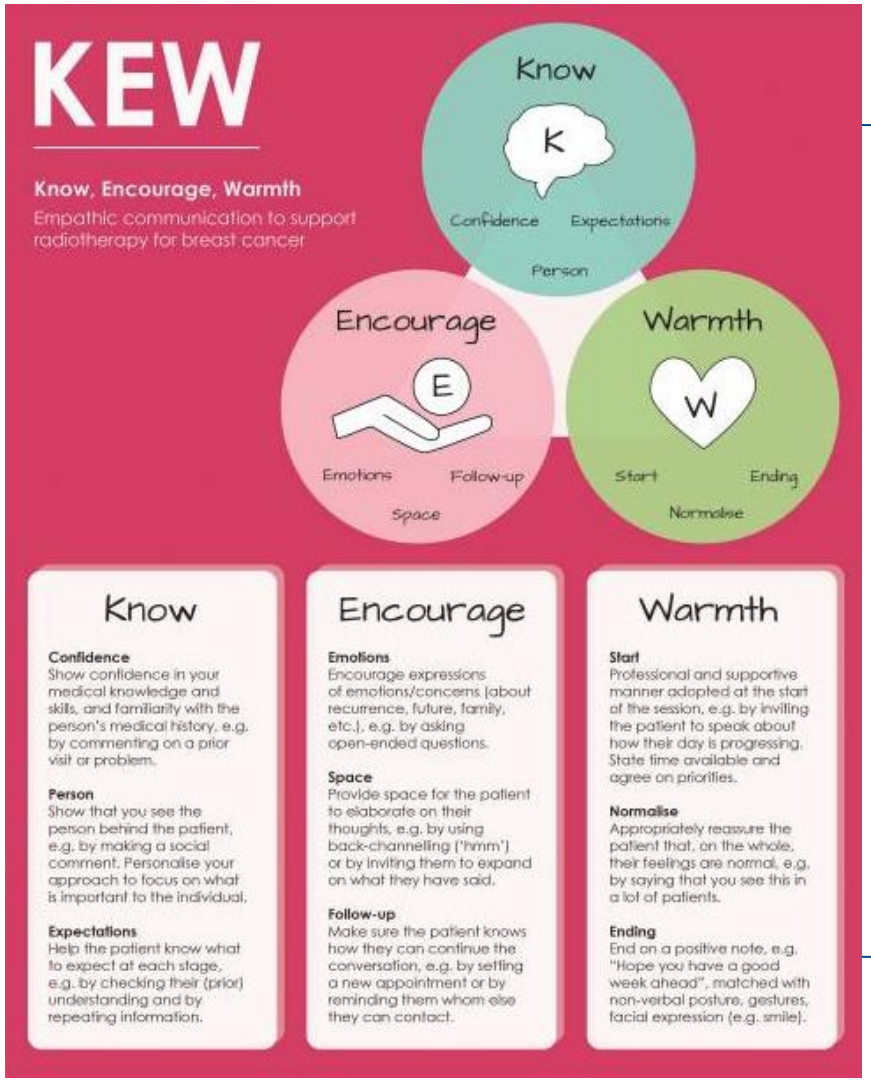
Purpose To evaluate the effectiveness and acceptability of a 6-week acceptance and commitment therapy (ACT)–based group programme on participants' fear of cancer recurrence (FCR), quality of life (QoL), psychological distress and psychological flexibility at the end of the programme and 12-week follow-up.

Methods A one-group, post-test service evaluation of a real-world psychological programme was carried out to evaluate collected outcome measures and attendance for a total of 21 groups facilitated between 2017 and 2019. Participants were breast cancer survivors who attended a 6-week group programme led by NHS clinicians. Descriptive statistics and repeated measures ANOVA analyses were carried out for each outcome measure. Attendance levels were examined to assess acceptability.

Results A total of 97 group participants who had completed curative treatment for breast cancer took part. Of whom, 89% completed at least 4 of the 6 weekly group sessions and 76% attended the 12-week follow-up session. Eighty-four (87%) participants returned outcome measures at all three time points relative to group participation (T1 = pre, T2 = post T3 = 12-week follow-up). Group participants were female, mean age 51.9 years. FCR was highest at T1 (mean 25.2, SD 4.7), reduced T2 (mean 21.2, SD 5.4) and further lowered T3 (mean 19.5, SD 6.2). This difference was statistically significant ($p < 0.001$). QoL was lowest at T1 (mean 62.4, SD 15.7), increased T2 (mean 71.7, SD 18.1) and further increased at T3 (mean 75.9, SD 17.5). This difference was statistically significant ($p < 0.001$). Psychological distress measures were shown to reduce, and psychological flexibility increased.

Conclusions This real-world evaluation of an ACT-based group programme led to improvements in FCR, QoL, psychological distress and psychological flexibility in this population. This evaluation provides basis for further investigation to determine if these results can be replicated by controlled research design across diverse populations.

Training developed by Radiographers in NHS Lothian



frontiers in Psychology

ORIGINAL RESEARCH
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Using Co-design With Breast Cancer Patients and Radiographers to Develop "KEW" Communication Skills Training

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Previous work (FORECAST) has shown that concerns of breast cancer patients after finishing radiotherapy are responsive to conversations with radiographers during the treatment period. This study seeks to further understand radiographer and patient experiences, determine shared priorities for improvement in clinical interaction and develop communication guidelines and training to help radiographers support patients.

Responding helpfully to Fear of Cancer Recurrence…

- Normalise, validate, space to listen without fixing
- Routine screening in post treatment pathway to open up the conversation and identify level of severity
- Provide or signpost to resources
- Pro-active management and discussion of how to manage anxiety and respond to physical changes
- Consider alongside other physical and psychological challenges
- Focus on what you can control – health behaviour change
- Consider peer support
- Clear referral pathway for specialist support if needed (3rd sector?)
- Training and support for HP's

Questions

Scan or click the QR code to ask a question:

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