CANCER RESEARCH UK

Blood cancer UK

NHS

Patient experiences & involvement in our work

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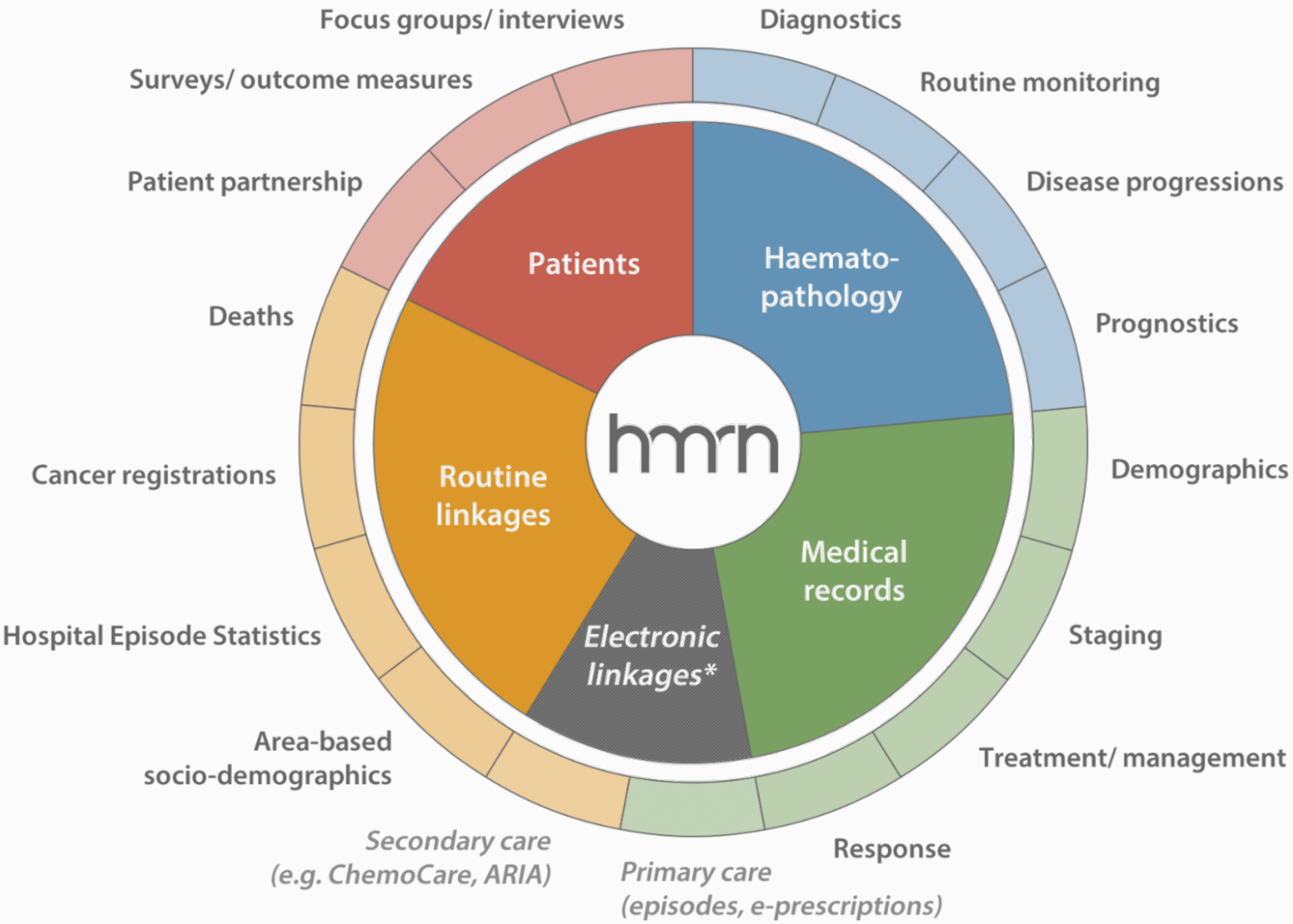
Focus on patient experiences



*Future

Our research areas

Measuring and counting disease:

- How many people get blood cancers?
- Who gets what?
- How are people treated?
- How do patients respond to treatment and why does this sometimes differ?

Exploring experiences of having disease:

- What happened in the time leading up to your diagnosis of blood cancer?
- What is it like to live with blood cancer on a day to day basis?
- Which issues are still a struggle for you?
- What would have improved the care you received?

Data collection


One-to-one interviews


Patients, relatives, clinical staff


Face-to-face


Group discussions


Single events

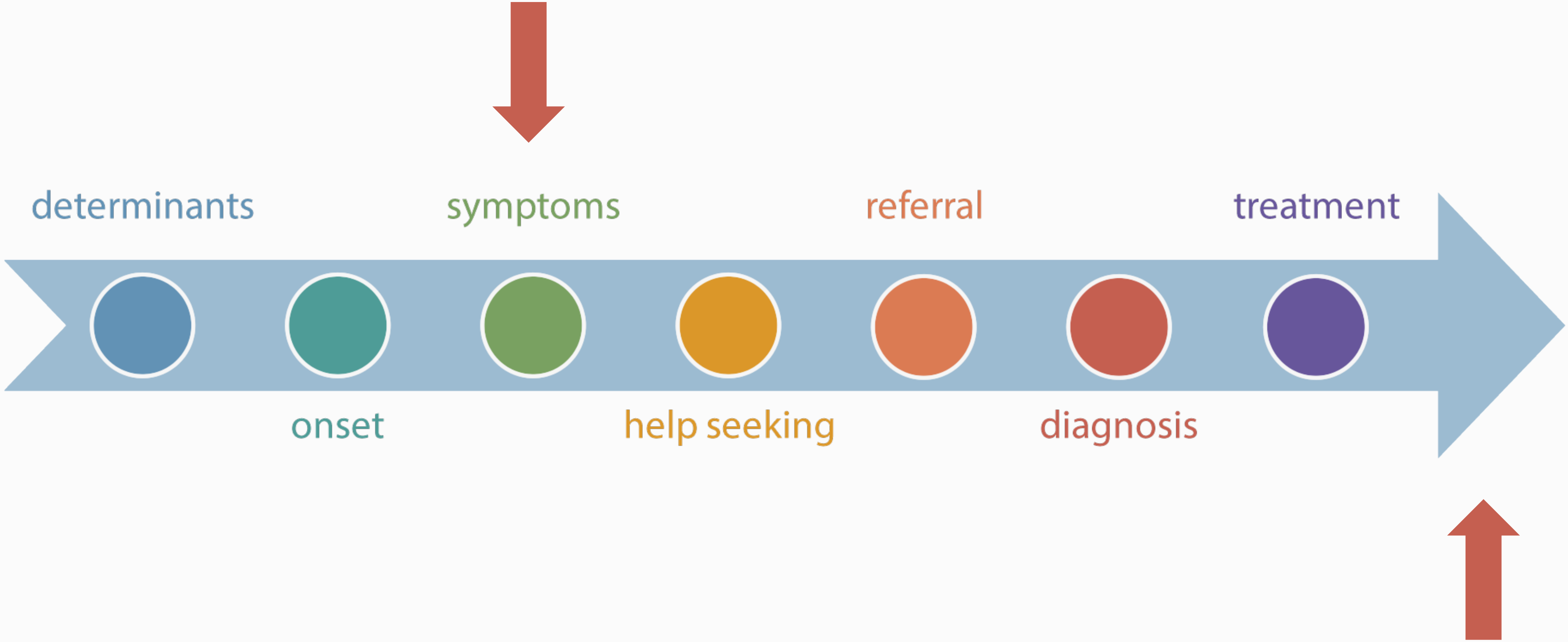

Online


Surveys

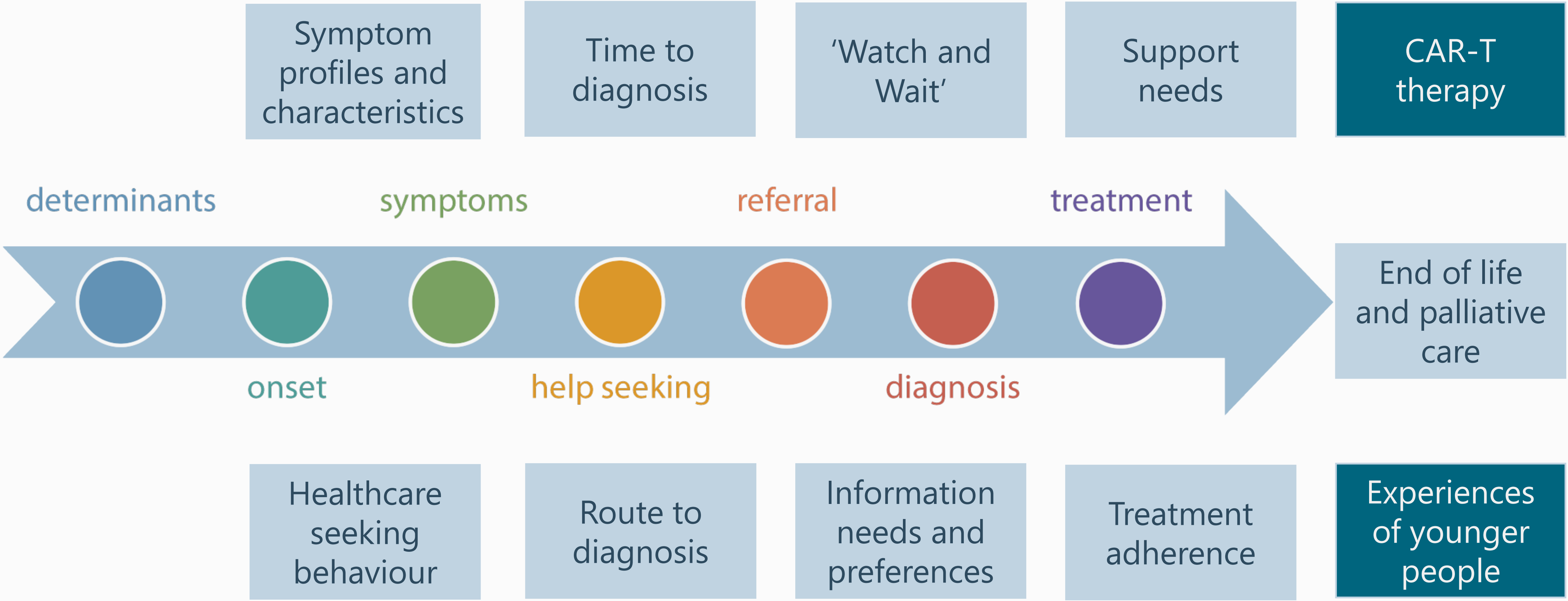

Multiple time-points


Telephone

Pathway and research areas



Pathway and research areas



Symptom profiles and characteristics

Time to diagnosis

'Watch and Wait'

Support needs

CAR-T therapy

determinants

onset

symptoms

help seeking

referral

diagnosis

treatment

End of life and palliative care

Healthcare seeking behaviour

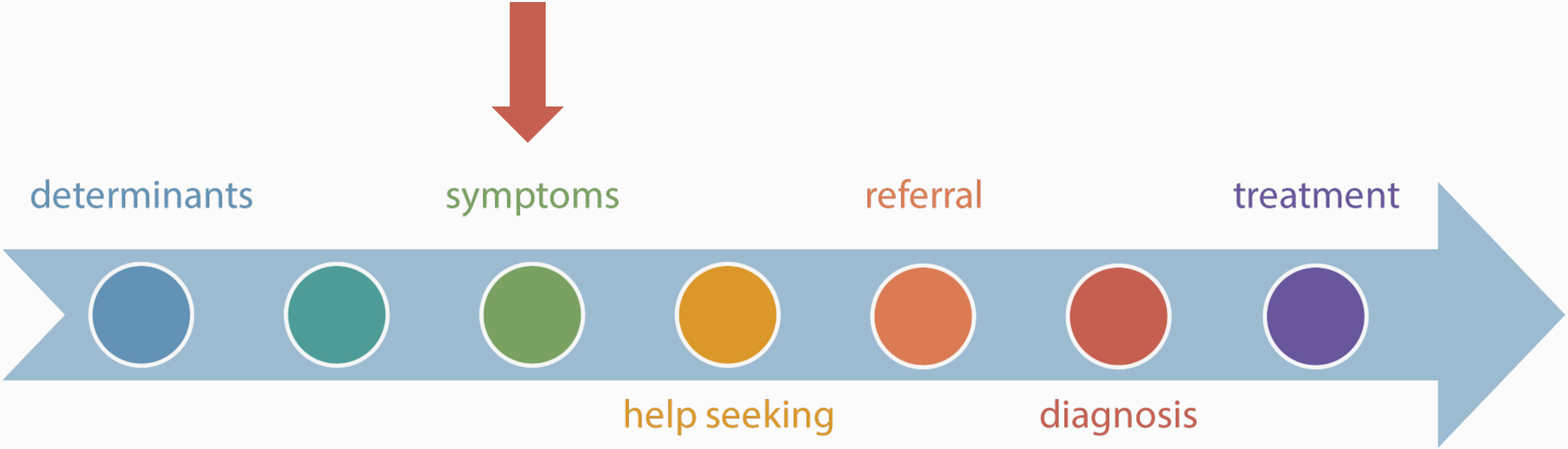
Route to diagnosis

Information needs and preferences

Treatment adherence

Experiences of younger people

Symptoms leading to diagnosis



determinants

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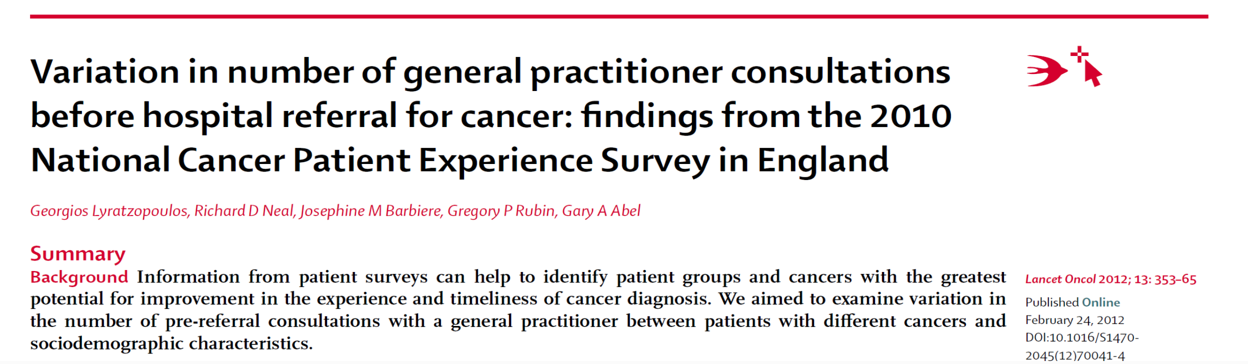
Symptom profiles and characteristics

GP visits before referral to hospital



Variation in number of general practitioner consultations before hospital referral for cancer: findings from the 2010 National Cancer Patient Experience Survey in England

Georgios Lyratzopoulos, Richard D Neal, Josephine M Barbiere, Gregory P Rubin, Gary A Abel

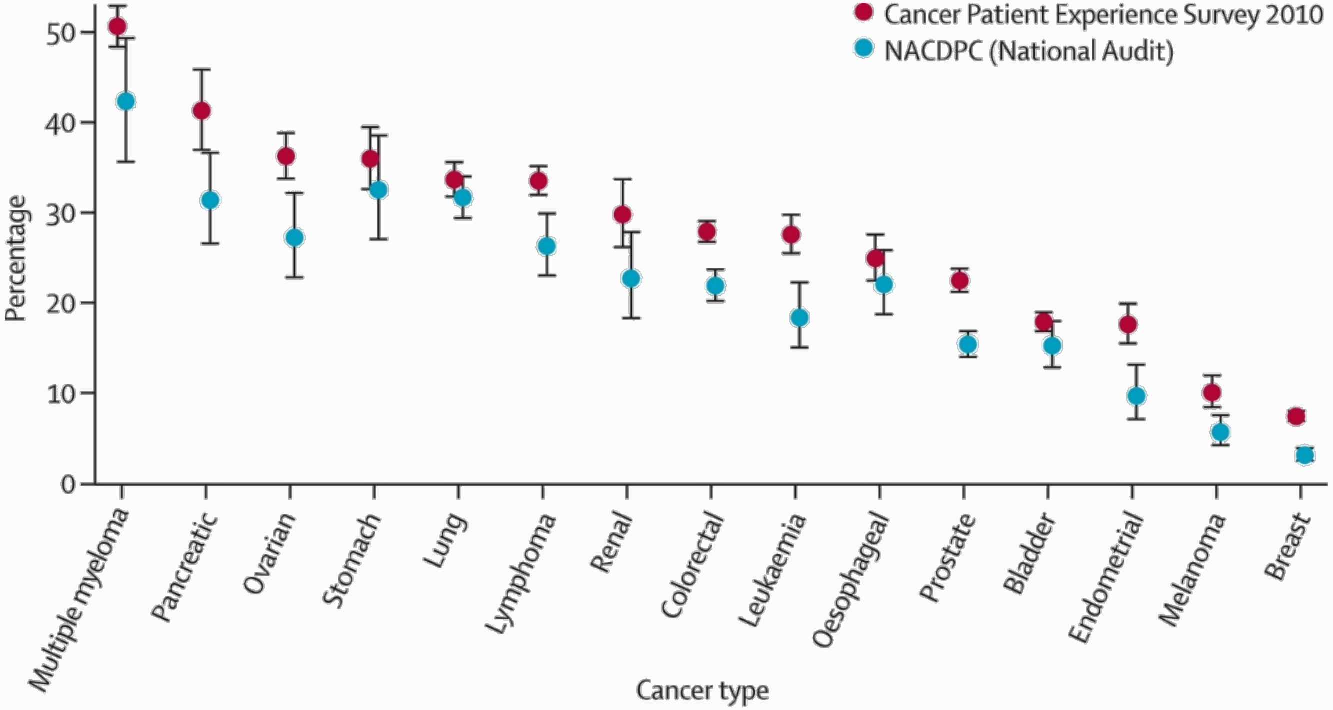
Summary

Background Information from patient surveys can help to identify patient groups and cancers with the greatest potential for improvement in the experience and timeliness of cancer diagnosis. We aimed to examine variation in the number of pre-referral consultations with a general practitioner between patients with different cancers and sociodemographic characteristics.

Lancet Oncol 2012; 13: 353–65

Published Online
February 24, 2012
DOI:10.1016/S1470-2045(12)70041-4

≥ 3 GP Consultations before hospital referral



Symptoms self-reported by patients in our study

General feelings of ill health

- ‘can’t put my finger on it’, ‘just felt rotten’, ‘under par’, ‘something wasn’t right’, ‘under the weather’
- ‘grotty’, ‘unwell’, ‘vaguely off’, ‘lousy’, ‘rough’, ‘terrible’
- ‘immunity whacked’, ‘run-down’, ‘one thing after another’

> ‘I ended up saying to the doctor “it's a feeling of malaise, I can’t explain how I feel”’

Tiredness/energy related symptoms: ‘fatigue’, ‘lethargy’, ‘tired’, ‘weak’, ‘lack of energy’, ‘apathy’

- **Characteristics** ‘debilitating’, ‘desperate’, ‘extreme’, ‘immense’, ‘prolonged’
- **Impact** ‘depleted’, ‘flattened’, ‘no reserve’, ‘running on empty’, ‘shattered’, ‘exhaustion’ ‘worn out’
- **Specific activities** work, family responsibilities, hobbies (gym, fitness, gardening)

Symptoms self-reported by patients in our study

- **Musculoskeletal pain, aching stiffness, fractures:** arms, back, chest, knee, legs, neck, ribs
- **Pain:** abdomen, groin, rectum, stomach
- **Lump/swelling:** sternum, armpit, neck, groin, stomach, mouth, jawline
- **Infections:** cold, flu, pneumonia, cough, trouble breathing, sore throat, mouth ulcers, sweating, shivers
- **Gastric**: loss of appetite/weight, indigestion, nausea, alcohol reaction, vomiting, bloating
- **Bleeding**: nose (‘pumping out’), gums, vaginal, bowel; bruising, dizzy, palpitations
- **Cognitive**: confusion, loss of concentration, memory loss, mistakes at work
- **Psychological**: low mood, irritable
- **Other**: itchy skin, rash, frothy urine, stroke, altered sensations, pins and needles, headaches, cramp
- **None!**

How patients said they interpreted their symptoms

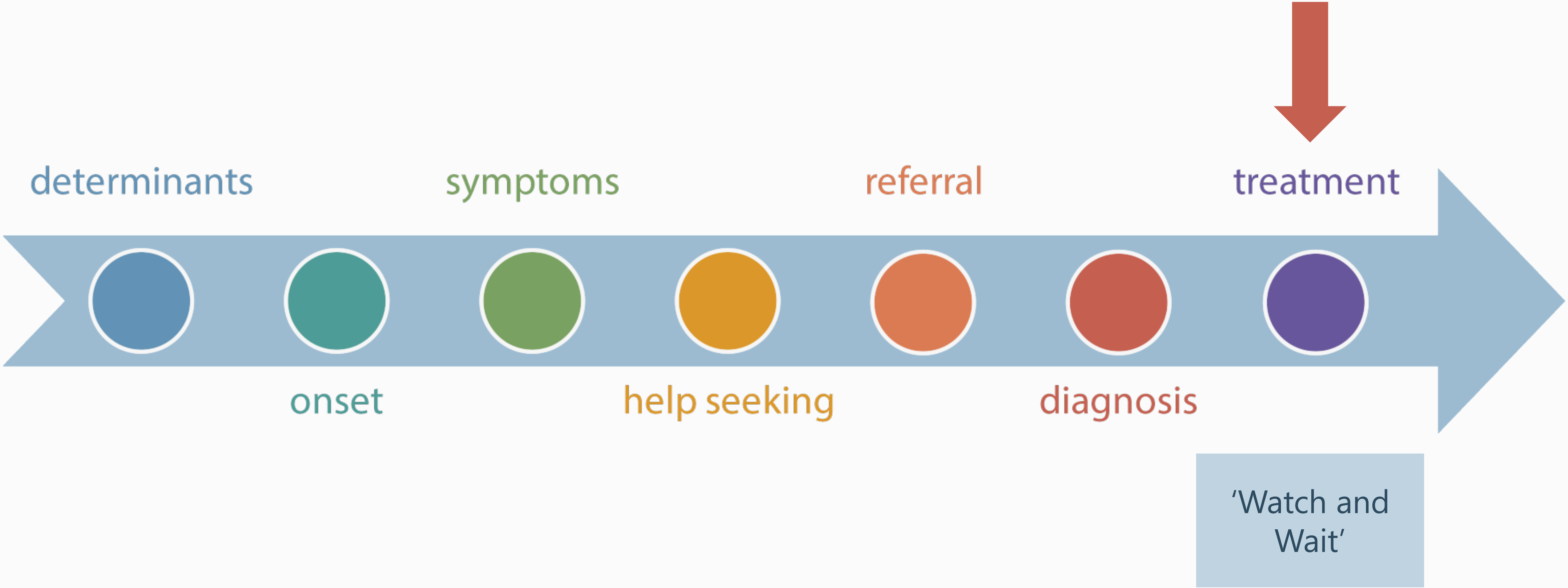
Illnesses and comorbidities

- Hernia
- Back trouble
- Hypochondria
- Depression
- Stomach cancer
- Vertigo
- Haemorrhoids
- Slipped disc
- Crohn’s disease
- Irritable bowel

Lifestyle and life stage

- Age/aging
- Menopause
- Fasting
- Overdone things
- Stress, hectic, worries, busy, rushing

Chronic blood cancers: 'Watch and Wait'



determinants

onset

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'Watch and Wait'

Chronic blood cancers: ‘Watch & Wait’

- Around 60% of blood cancers are considered ‘chronic’
- Many cannot be cured, but can be managed on ‘Watch & Wait’
- This can continue for months, years, decades
- We interviewed patients and relatives to explore their experiences

Experiences of chronic blood cancer

Relief

- Reassuring phrases

‘Slow growing’

‘Very treatable’

‘Not life-threatening’

‘Can take months, decades to develop’

‘Go and live your life’

- Seen as ‘positive’; chose not to dwell on diagnosis

‘A big ray of hope’

Lack of treatment

- Many said they expected treatment soon after diagnosis
- Most thought early treatment is important for people with cancer
- Terminology impacted this (e.g. ‘*leukaemia*’)
- People struggled waiting for the cancer to get worse

‘it’s hard to understand,
you have something
really frightening, yet
nothing happens’

Uncertainty

- Caused by not knowing *'if'* and *'when'* treatment might be needed.
- What people were told:

'nothing might happen during your lifetime'

'sometime or other, chemo will have to come in'

'you cannot predict what's going to happen, it may never ever come back. It may come back tomorrow. It's completely uncertain'

'it could come back 5 or 10 years down the line, it's a raffle, you could be lucky, or it could come back'

Anxiety and distress

- High levels of anxiety and depression

‘an awful time for me’,

‘it’s just horrible being in this position’.

- Preoccupied and overwhelmed

‘fear of not knowing what’s going on’

- Intense and prolonged, affected ability to plan for the future

Involvement in our work

Two types

- As participants (completing questionnaires, interviews etc.)
- As co-workers, in partnership with researchers

What does it involve?

- Working with/alongside researchers and contributing to the process.

Sources of involvement in our work

- **Patient Support Group**
  - ‘Sounding board’
  - Hear patient experiences
  - Feedback our findings

- **Patient Partnership**
  - Contains thousands of people
  - Can contact for further research purposes
  - Overseen by a Steering Committee **(we are about to start recruiting again!)**

Benefits you bring to our work by being involved

- You can **make a difference** and improve care in the future
  - by **giving us insight** into what it is like to live with a particular illness day to day, or use healthcare services
  - Telling us what is **relevant and important** to you, so our studies are more likely to have **impact**.
  - Helping us decide the best way to **recruit** participants and **conduct** studies, so they are more likely to run better.

Thank you to the patients and families who take part in our research, and our funders and NHS colleagues

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Department of
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