



Twenty years on from ‘nothing about me’ Systemic anti-cancer therapy in the last 30 days of life

Professor Annmarie Nelson
Scientific Director

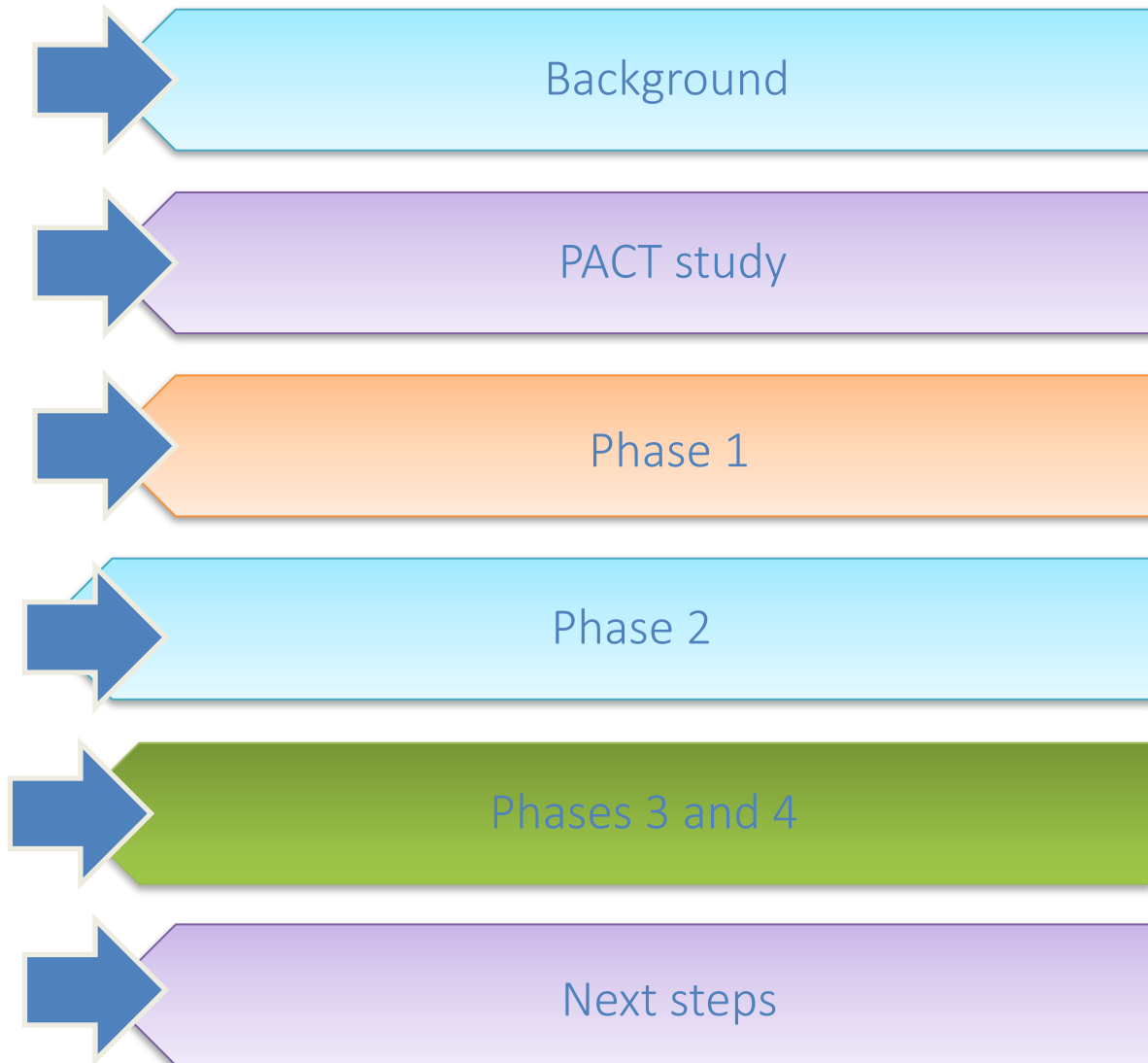
Marie Curie Palliative Care Research Centre
Cardiff University School of Medicine



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Overview



Advanced Lung cancer

- 44,500 lung cancer cases in UK per year
- Aged 70-74
- Non small cell lung cancer 85% of cases
- Median survival 6-8 months
- Systemic treatment for unresectable stage III and IV lung cancer. E.g. four to six courses of treatment over three to six months.
- 30-day mortality rates as a national clinical indicator of avoidable harm from SACT (10%)

30 day mortality

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

- Inappropriate SACT in 154/435 (35%)
- 43% of patients who died within 30 days of SACT suffered grade 3 or 4 treatment related toxicity
- 85% admitted to hospital in last 30 days of life.



Healthcare professionals' motivations:

- Oncologists - late chemotherapy is patient driven.
- Palliating emotional distress.
- Additional symptoms, increased use of other aggressive treatments, and worsening quality of life.
- Compromises access to specialist palliative care.
- Medical futility, cost and avoidable harm.

What influences patients' decisions

Patients not choosing SACT

- Greater acceptance of terminal status
- Focus on present
- Time with family
- QoL/avoid side effects
- Open communication

Patients choosing SACT

- Less accepting or aware of prognosis
- Focus on the future
- Time with family
- Ambivalent, denial

(MSc Palliative Medicine Dr Stephen Miller 2014)

Patients' awareness

Just five percent of patients acknowledge “end stage ... incurable” cancer.

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ORIGINAL REPORT



Epstein, Eileen M. O'Reilly, Holly G. Prigerson, Paul K. Maćiejewski, Eileen M. O'Reilly, Holly G. Prigerson, Paul K. Maćiejewski, Research on End-of-Life Care, University, and Weill Cornell New York, NY

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Disclosures of potential conflicts of interest and author contributions are found in the article online at [jco](#). Author contributions are found at the end of this article.

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Discussions of Life Expectancy and Changes in Illness Understanding in Patients With Advanced Cancer

Andrew S. Epstein, Holly G. Prigerson, Eileen M. O'Reilly, and Paul K. Maćiejewski

ABSTRACT

Purpose

Accurate illness understanding enables patients to make informed decisions. Evidence of the influence of prognostic discussions on the accuracy of illness understanding by patients demonstrate the value of discussions.

Methods

Recent and past oncology provider-patient discussions about prognosis/life expectancy were examined for their association with changes in illness understanding by patients. Patients (N = 178) with advanced cancers refractory to prior chemotherapy whom oncologists expected to die within 6 months were interviewed before and after a visit in which cancer restaging scan results were discussed. Illness understanding scores were the sum of four indicator variables: patient illness acknowledgment, recognition of incurable disease status, knowledge of the advanced nature of the disease, and expectation to live months as opposed to years.

Results

Before the restaging scan visit, nine (5%) of 178 patients had completely accurate illness understanding (ie, correctly answered each of the four illness understanding questions). Eighty-eight patients (10%) reported only recent discussions of prognosis/life expectancy with their oncologists; 68 (38%) reported only past discussions; 24 (13%) reported both recent and past discussions. Eighty-eight (38%) reported that they never had discussions of prognosis/life expectancy with their oncologists. After adjustment for potential confounders (ie, education and race/ethnicity), we identified significant, positive changes in illness understanding scores for patients in group 1 who reported recent only (least-squares mean change score, 0.62; 95% CI, 0.23 to 1.01; $P = .002$); both recent and past (least-squares mean change score, 0.37; 95% CI, 0.04 to 0.70; $P = .002$); and discussions of prognosis/life expectancy with their oncologists.

Conclusion

Patients with advanced cancer who report recent discussions of prognosis/life expectancy with their oncologists come to have a better understanding of the terminal nature of their illnesses.

Palliative care

Early integration of palliative care with standard oncologic care in patients with metastatic non-small-cell lung cancer:

No chemotherapy =

- increase in survival time by approximately two months
- improved quality of life and mood

Proof of Principle for Early Palliative Care

The NEW ENGLAND JOURNAL *of* MEDICINE

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

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Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H.,
J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

PACT study: An Intervention to Support Advanced Lung Cancer Patients and Their Clinicians When Considering Systemic Anti Cancer Therapy.

Study CI: Annmarie Nelson
Co-applicants: S Sivell; S Noble; A Byrne; Dr Jason Lester
Research partners: David Jones; Lesley Smith
Funder: The Velindre Stepping Stones Appeal (2013/009)



PACT: protocol paper

Open Access

Protocol

BMJ Open Development of an intervention to support patients and clinicians with advanced lung cancer when considering systemic anticancer therapy: protocol for the PACT study

Despina Anagnostou,¹ Stephanie Sivell,¹ Simon Noble,¹ Jason Lester,² Anthony Byrne,³ Catherine Sampson,¹ Mirella Longo,¹ Annmarie Nelson¹

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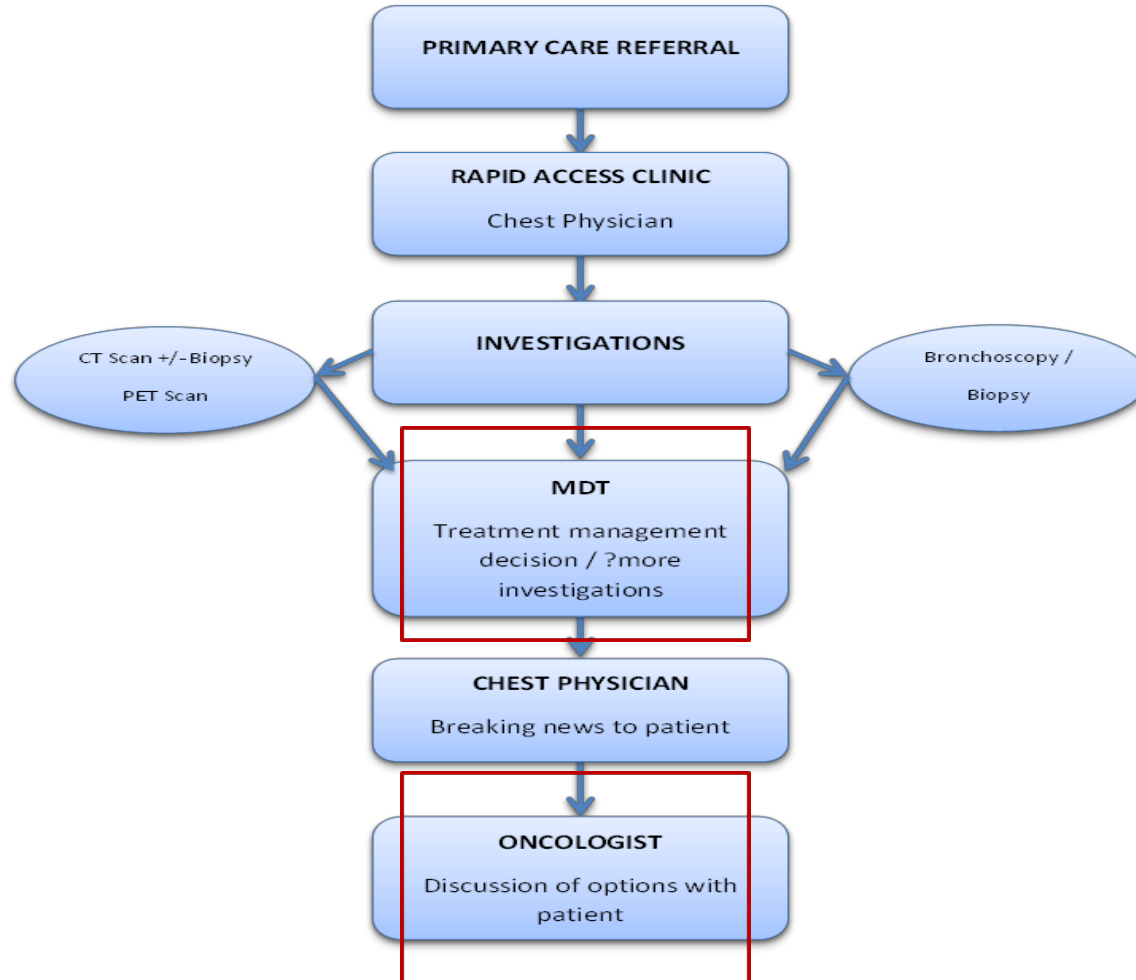
ABSTRACT

Introduction Patient-centred care is essential to the delivery of healthcare; however, this necessitates direct patient involvement in clinical decision-making

Strengths and limitations of this study

▶ A multimethod qualitative approach, tailored to each phase research question and data type, is used to

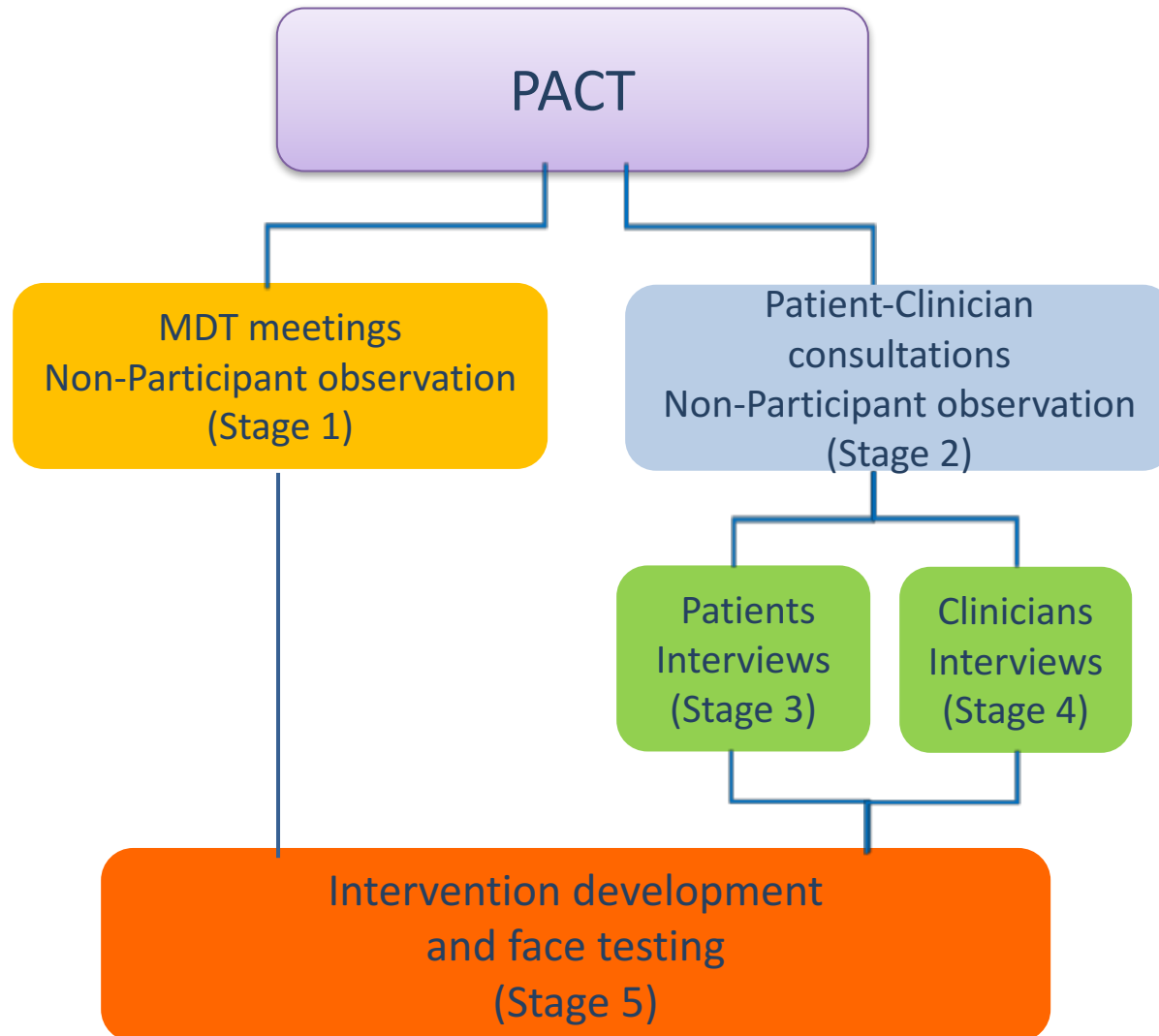
PACT: Lung Care pathway



PACT: Aims

- To identify the information and decision support needs of patients with incurable lung cancer
- To design an intervention to facilitate clinicians' discussion of the risks and benefits of the available treatment options including systemic anti-cancer therapy (SACT) and/or referral to, or integration with, palliative care.

PACT: Study design



Marie Curie

Care and support through terminal illness

PACT: Participants

Stage 1-4 recruitment		
Health care professionals	51	
Families	10	
Patients with advanced SCLC	10	
		Total: 71
Stage 5 recruitment (consensus)		
Consensus focus groups	33	
		Total: 104
Data collection events:		
Observation of MDT meetings	13	
Observation of consultations	14	
Patient- carer interviews:	10	
Clinician interviews	17	
Focus groups- consensus	3	
		Total 47

PACT: Multi-methods, layered analytic framework

All stages:

Thematic analysis.

Stage 1 MDT:

Mediated discourse analysis
of key turning points.

Stage 2 Oncology clinic:

Option grid framework.

Stage 3 Patient interviews:

NA of key turning points.

Stage 4 Clinician interviews:

NA of key turning points.

Pathology slides

Remote attendees

Radiology scans

CANISC

Door

Radiologist



Pathologist

Oncologist

CNS

Tables with
hardcopy
patient
files on

Chair - Chest
Physician

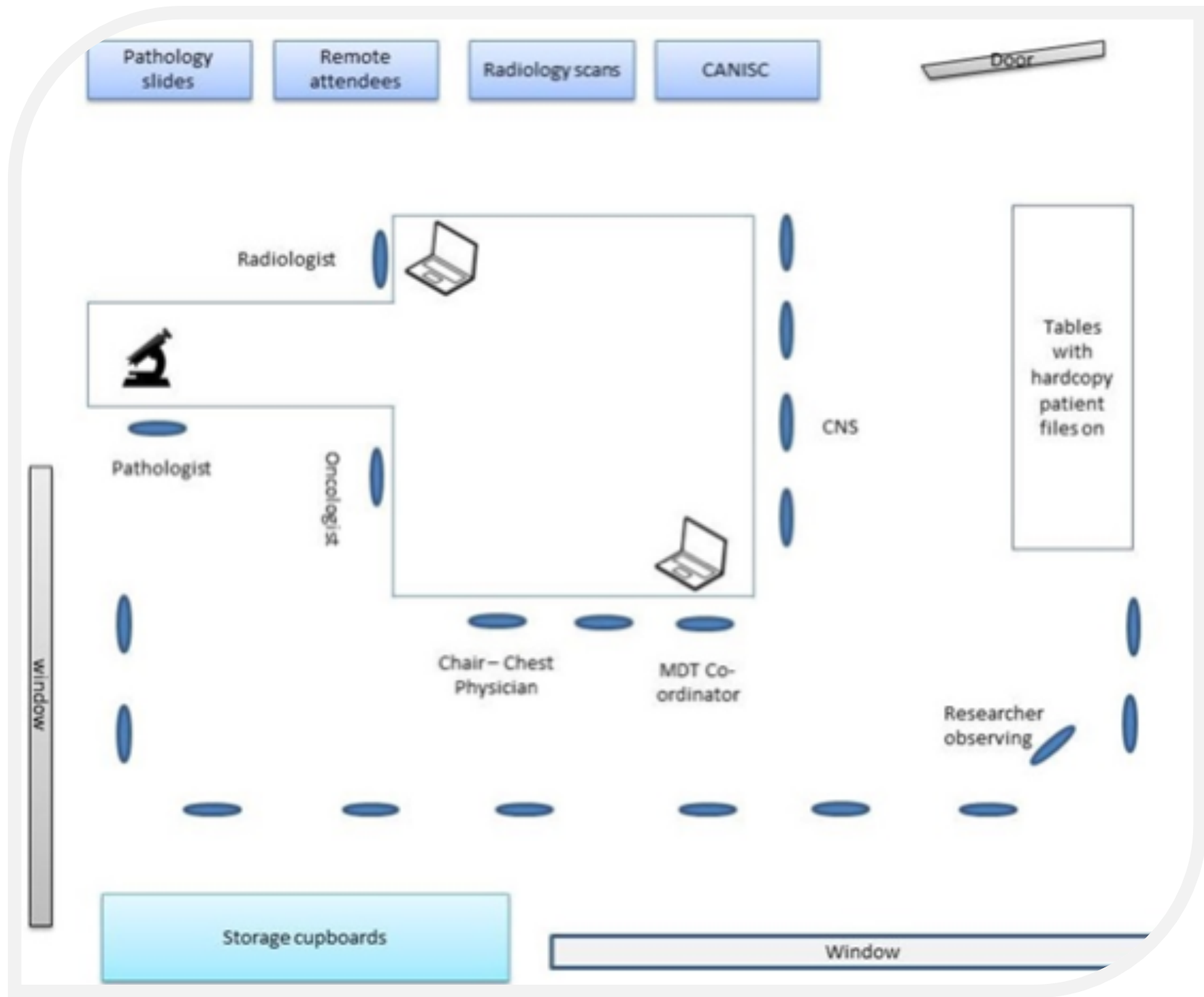
MDT Co-
ordinator

Researcher
observing

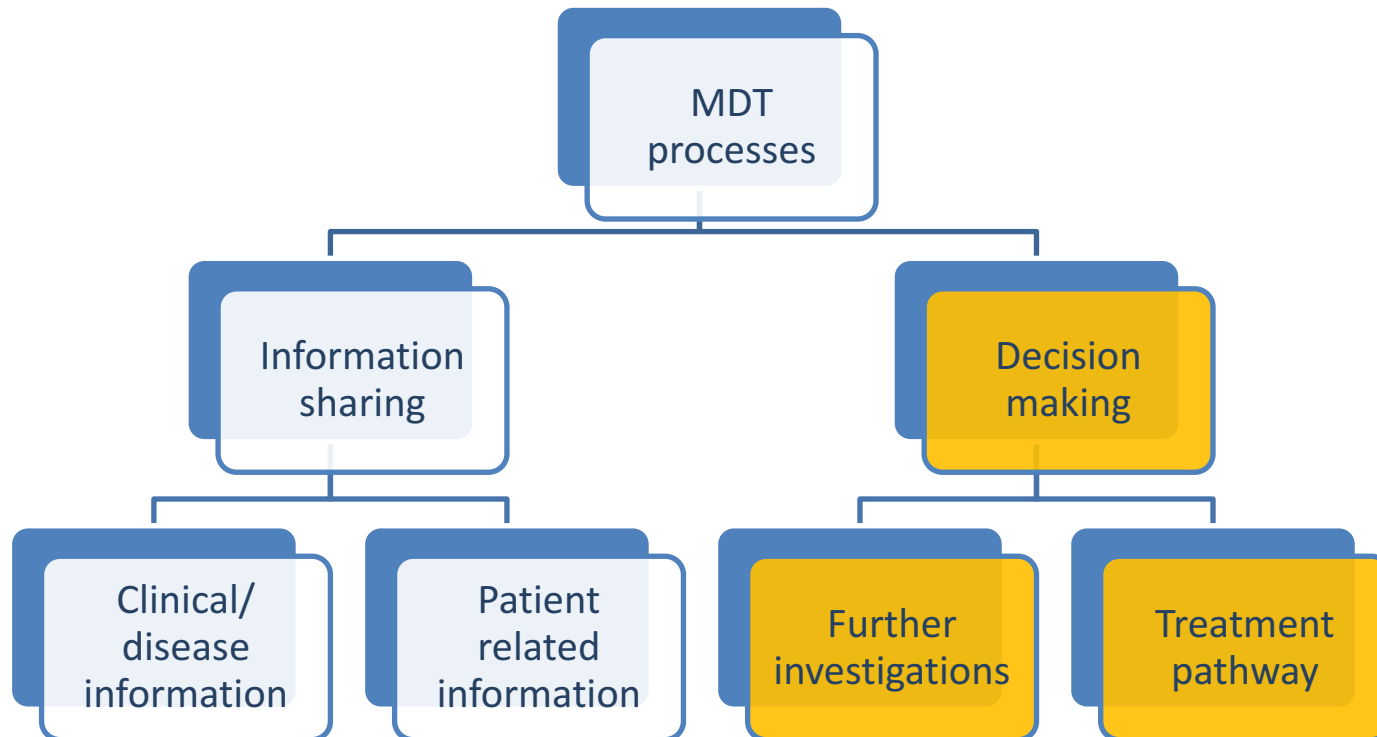
Storage cupboards

Window

Window



Phase 1: Multidisciplinary Team Meeting



Phase 1: Multidisciplinary Team Meeting

Patient presentation



Phase 1: Multidisciplinary Team Meeting

0 - Fully active, able to carry on all pre-disease performance without restriction.

1 - Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light house work, office work.

2 - Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours

3 - Capable of only limited self-care; confined to bed or chair more than 50% of waking hours.

4 - Completely disabled; cannot carry on any self-care; totally confined to bed or chair.

5 - Deceased

Phase 1: Multidisciplinary Team Meeting

Chest physician: *We're discussing a sixty five year old chap, performance status is zero always, wheelchair bound.*

Palliative consultant: *Can he get out of the wheelchair?*

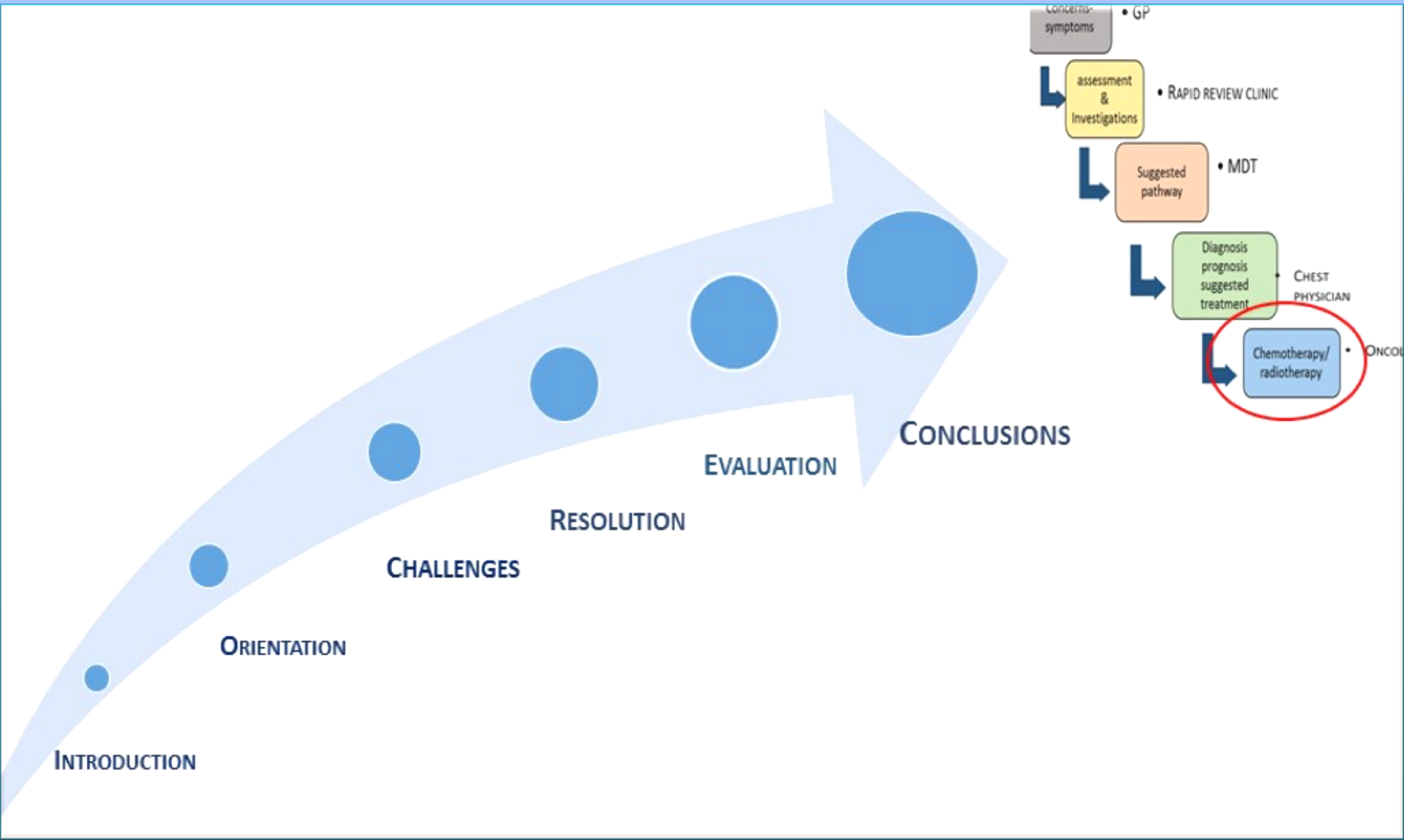
Chest physician: *He can yes ... he's performance status one to two we had an interesting discussion with (oncologist) about how we assess a performance status in this situation... it is very hard*

Palliative consultant: *...people who'd have strokes on a good day would meet those criteria so yeah it has to be in context don't it?*

Phase 1: Multidisciplinary Team Meeting

- Patient social circumstances, priorities and preferences are often not known
- The MDT functions as forum where complexity emerges and is resolved through the shared expertise of the team
- MDT further defines the factors influencing dynamic decision making process i.e. resources, time, key personnel, information sources
- Performance status defines fitness for treatment
- Streamlining and triage

Phase 2: Oncology clinic



Phase 2: Oncology clinic

Oncologist: *I've been asked to see you by the chest team cos I know you recently been in hospital so I've seen all your images and seen your notes etc so really what we need to do is talk about some treatment options today*

Patient: *Yeah fine*

Oncologist: *Is that what you were expecting?*

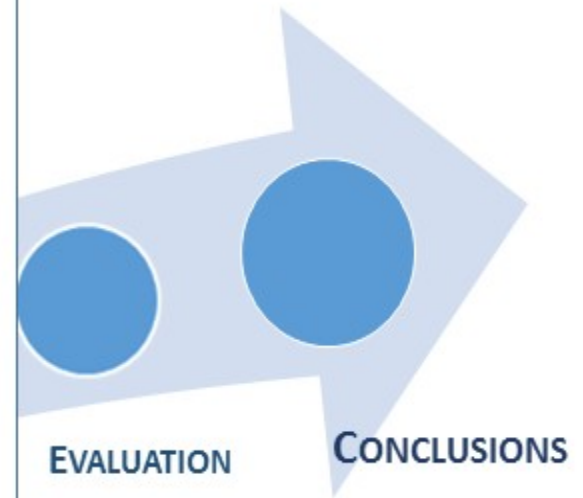
Companion: *That's what he wanted*

INTRODUCTION

ORIENTATION

EVALUATION

CONCLUSIONS



Phase 2: Oncology clinic

Oncologist: *What have they explained to you about what's going on here?*

Patient: *Nothing, nothing really*

Oncologist: *Okay cos when you were on the ward they didn't have an opportunity to discuss your results with you then?*

Patient: *Well I seen so many doctors*

Oncologist: *It gets confusing doesn't it? ... if I talk you through what the aims of the treatment are a bit then we can discuss what your views are about it obviously but the main aim of the treatment will be to try and shrink the cancer to try and reduce what we can see on the scans prevent it hopefully spreading but what it can't do is get rid of it all. So we have to acknowledge that with the information that we've got from your CT scan that we're not looking at a situation at which we can cure you so therefore we're not looking at surgery as a treatment option so was that something you expected to hear or?*

Patient: *Don't know, don't know anything yet*

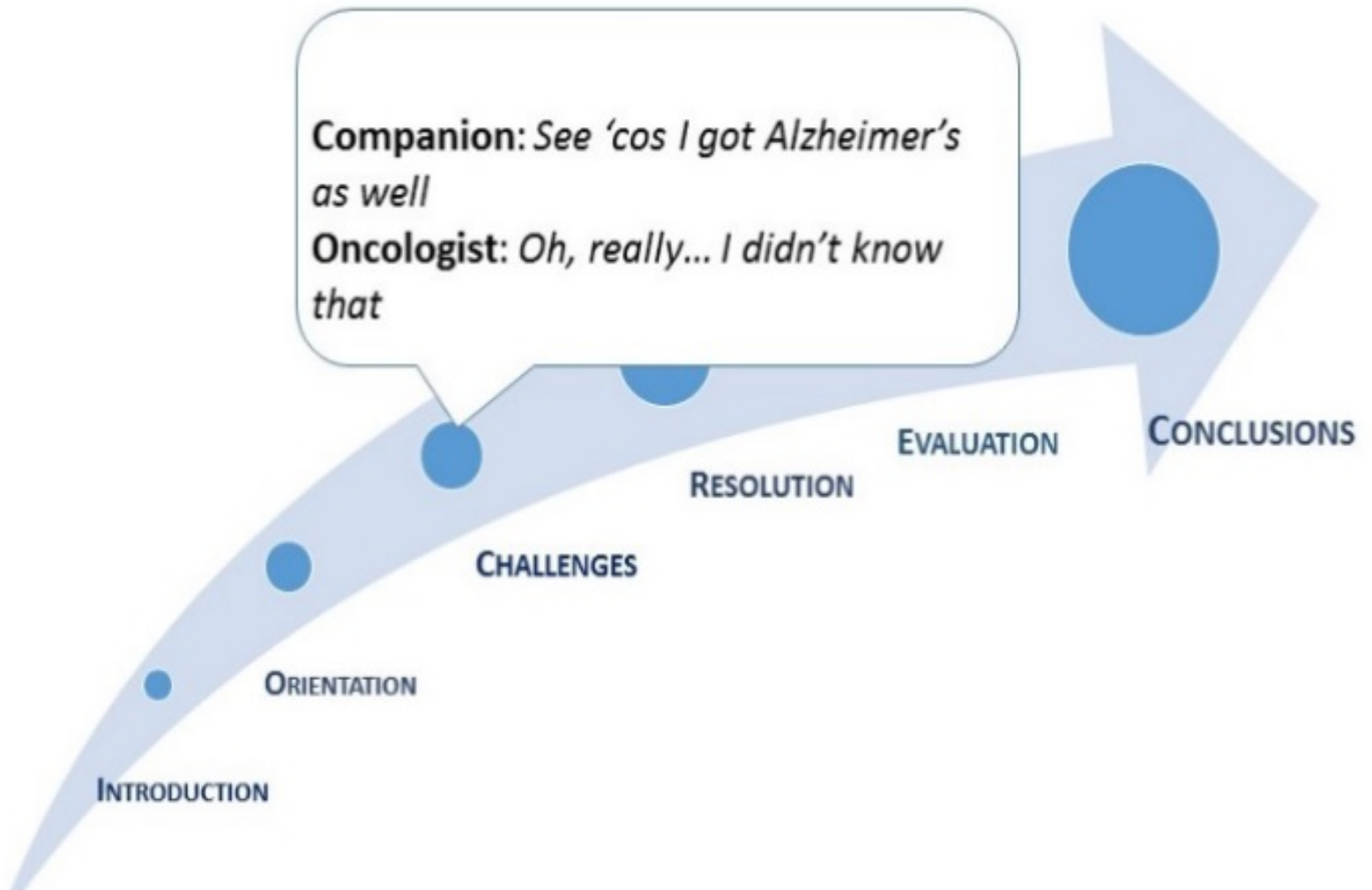
CHALLENGES

ORIENTATION

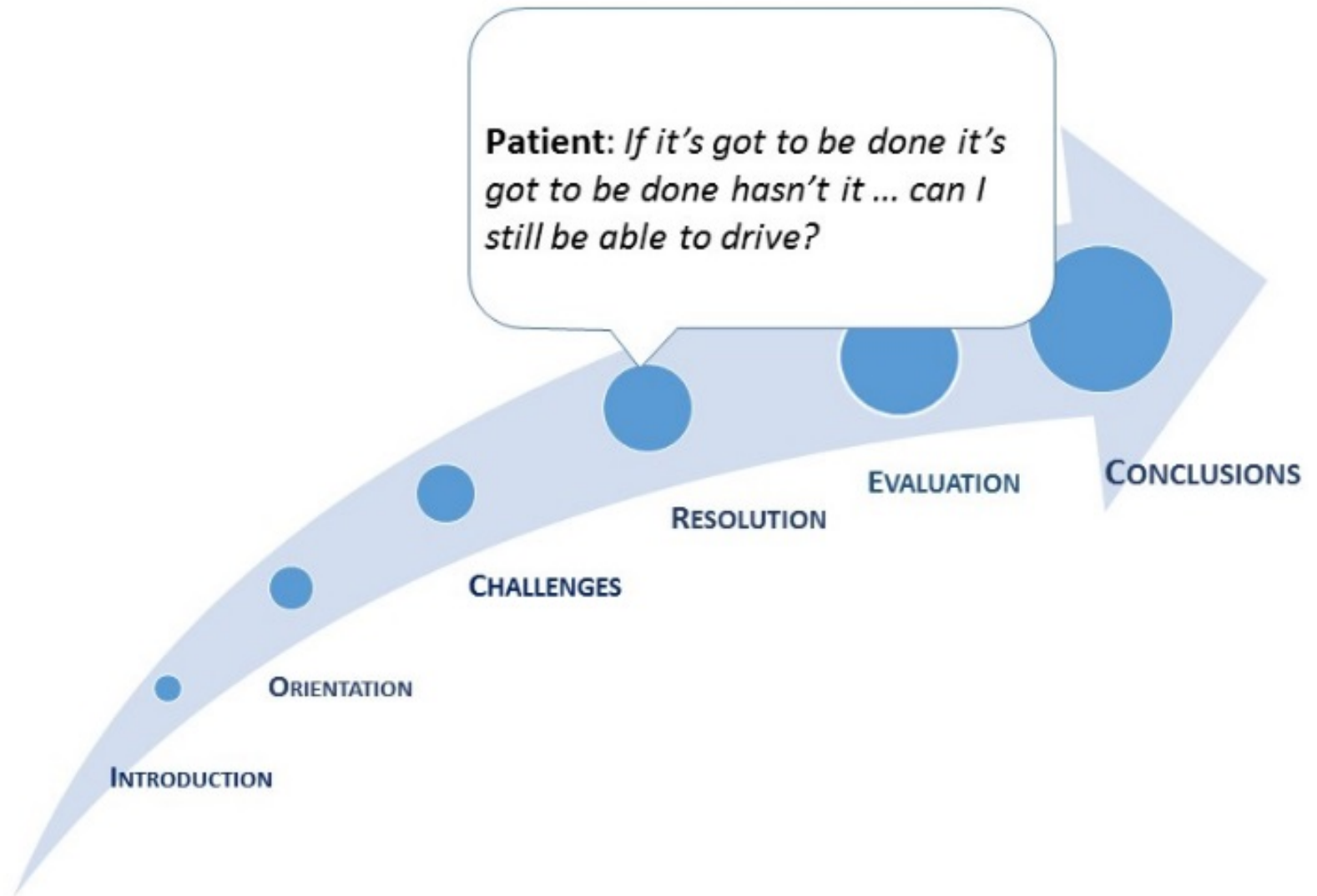
INTRODUCTION

IONS

Phase 2: Oncology clinic

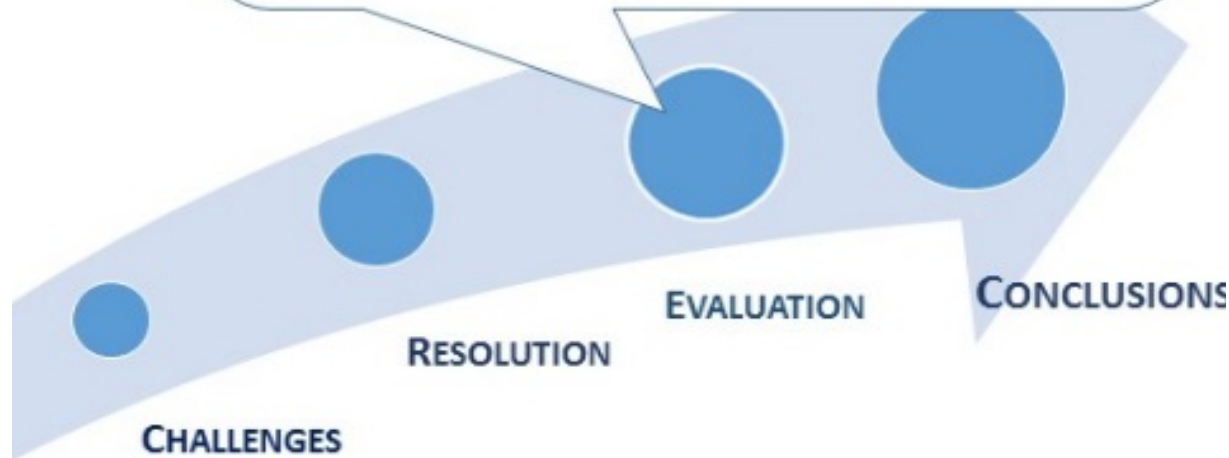


Phase 2: Oncology clinic



Phase 2: Oncology clinic

Patient: *I don't want to give up ... we got too much to do haven't we? ... As long as I can get my breathing under control I'm happy. I go out in my garden, cut my grass and that's all I want to do*



Phase 2: Oncology clinic

Patient: *I focus on trying to control my breathing ... that's all I want to do ... she got Alzheimer's. I got to look after her, it's what I do.*

EVALUATION

CONCLUSIONS

The Grey Area

Phases 3 and 4 Interviews



Performance status

Phases 3 and 4 Interviews

The tough one is a patient, the tears rolling down their face, saying 'I want treatment, I don't care if there's a 90% chance I'm going to die and there's a 1% chance of benefit, I want the treatment'

- Because performance status is not that difficult is it? You just put yourself in one of a couple of boxes against what you are doing.

Priorities

Phases 3 and 4 Interviews

I think (patient) doesn't want to ask too much, and so let's focus on treatment.. which is why often patients psychologically collapse after their treatment, because when they're not having treatment, then they really do come up against this what's my prognosis and what's happening next

That's what they've been led to believe. They've come in here to talk about treatment. They don't really want to hear more about prognosis and diagnosis which we expect has been dealt with before they come in.

Priorities

Phases 3 and 4 Interviews

Patients

- Expectations, relationships, everyday life, what happens next, family events, positivity and hope

Clinicians

- Rapport, time, ability to tolerate treatment, health status, history, lifestyle and causes, symptoms, patient understanding of condition.

Palliative

Phases 3 and 4 Interviews

- Chemo = active treatment
- Term palliative reserved for no chemo option

Companion: *What's that word you said then, palliative?*

Oncologist: *What it means is to cloak, is to kind of just cover up and suppress and control essentially*

Companion: *So it means it's not a cure. It's just trying to slow things down. I got it confused...*

Palliative Phases 3 and 4 Interviews

Oncologist: *And have you seen the palliative care consultant?*

Oncologist: *Okay, anyone from the community team at all?*

Patient: *No*

Oncologist: *Okay, but you have been referred to the pain specialists. Well they're the palliative care team they are called, so they are experts in any symptoms that people get from cancer, pain being one but they'll also look after you for **anything else that's needed as well.***



Palliative

Phases 3 and 4 Interviews

Oncologist: *The aim of the chemotherapy would be to try and control the cancer and in some cases it does actually shrink it down ... you were saying about the pain and discomfort and your breathing being a little bit worse ... even though it has side effects some people actually feel better on chemo cos it can improve your quality of life if it works ... but unfortunately some people feel so poorly that you know that we don't think that we're doing the right thing.*



Prognosis

Phases 3 and 4 Interviews

During the consultation

Oncologist: *So what do you think about all of that?*

Patient: *Well, I suppose it's what sort of expected. **What I am concerned about is prognosis.***

It's that sort of 'How long' question

Oncologist: Companion: *We were going to rephrase that*

Patient: *Oh yes. **We have a holiday booked next year***

Companion: *So, rather than say specifically, what are the chances of going on holiday next year?*

Oncologist: *If I'm honest the majority of patients with a cancer as advanced as yours, even with treatment, would **not be alive in a year***

Companion: *Gosh*

Patient: *Right. **That's a bit of a shock.***

Decision as process for the patient

Breaking the news
Information
Honesty

pres
Informa

Impact of
treatment on
everyday
quality of life

Life context and
autonomy
Experiential knowledge

Diagnosis with chest physician

I asked her and she told me and she was absolutely amazing. Because she was so honest and open with me and I need people, I need to know the truth. I don't, I don't like thinking that there's something else and they're not going to tell me. I need to know the truth... She was a lovely, lovely lady. I felt so comfortable in with her and I, I just felt that I could ask her anything that I wanted to ... and I wasn't going to make myself look silly for asking questions she'd probably heard fifty thousand times before. I felt good that I could talk to her that I could ask her these questions and that she'd answered me honestly.

Decision as process for the patient

Breaking the news
Information
Honesty

Time pressure
Information

Impact of treatment
everyday
quality of life

Life context and autonomy
Experiential knowledge

Oncologist about radiotherapy

There are some side effects it can make you feel tired... mild skin reaction. Mild sunburn ... It can cause a bit of swelling, a little bit of inflammation so some people notice that their cough gets a little worse or maybe the breathing gets a little worse during the treatment and that can last for a few weeks following the treatment as well. The other thing is because we're targeting the x-rays in the middle as well as the right side of the lung ...so you can get a sore swallow or difficulty swallowing during the treatment ...Most people go through the radiotherapy with very small amount of side effects. It's not particularly toxic and I think hopefully it will help with your breathing and your pain.



Care and support
through terminal illness

Decision as process for the patient

Breaking the news
Information
Honesty

Time pressure
Information

Impact of treatment on everyday quality of life

Life context and autonomy
Experiential knowledge

Patient experience of radiotherapy

I've had the radiotherapy. I had that for um, fourteen days I think that was horrendous. Horrendous... it was horrendous it, it was in three different places... And then for a week later I couldn't eat or couldn't drink, because my oesophagus was all swollen and inflamed. So nothing would go down, oh it was horrendous but touch wood I'm feeling so much better now.



Care and support
through terminal illness

Decision as process for the patient

Breaking the news
Information
Honesty

Time pressure
Information

Impact of treatment on
everyday
quality of life

Living with
autonomy
Experiential knowledge

Patient reflection about treatment

I'm very dubious about having chemotherapy ... Because the radiotherapy was bad enough and I think if the chemotherapy is even worse I'm going to be so weak and I don't want to be like that ... so this is my biggest goal at the moment, it's just to get to Christmas like I am now ... after Christmas I would probably weigh up the pros and cons but I'd need to speak to, um, oncologists a lot more before I say yes, I would have the chemotherapy.



Care and support
through terminal illness

Decision as process for the patient

Breaking the news
Information
Honesty

Time pressure
Information

Impact of treatment
every
quality of

Experiential

Life experience and autonomy

People are not making decisions for me.... I've been here}, out of a {several decades} abusive marriage... people say to me, oh you're just being brave. I'm not being brave. I'm not brave. I'm exactly the same as every other soul in this land. I don't want to die. I, I don't want to leave everything ... I'm terrified but I will get there and I will fight it for as long as I can fight it and when the time comes then I hope I die peacefully and I'm not suffering too much and that's I think that's all anybody can ask out of life.



Care and support
through terminal illness

PACT summary

- Complex treatment options with a need to balance risks/benefits
- Patients' misunderstanding of the extent of disease, prognosis, purpose of consultations, and aims of treatment
- Treatment decision making should be framed within the patient's individual context. Patients preferences are poorly predicted
- WHO performance status is not a surrogate for function and task performance
- Missed opportunities for sharing relevant information. Better links between chest physician and oncologist to manage expectations
- Terminology, hope and communication
- Avoidable harm.

Improved pathway

Common to the all clinical pathways

- Patients should be able to express priorities
- Patients should list preferences
- Functional status should be assessed and recorded
- Quality of life should be measured and recorded
- The main carer should be able to express priorities
- The patient should receive a summary of the consultation
- Feedback from the consultation should include information about priorities and preferences
- Feedback from the consultation should include information about the care and support network around the patient

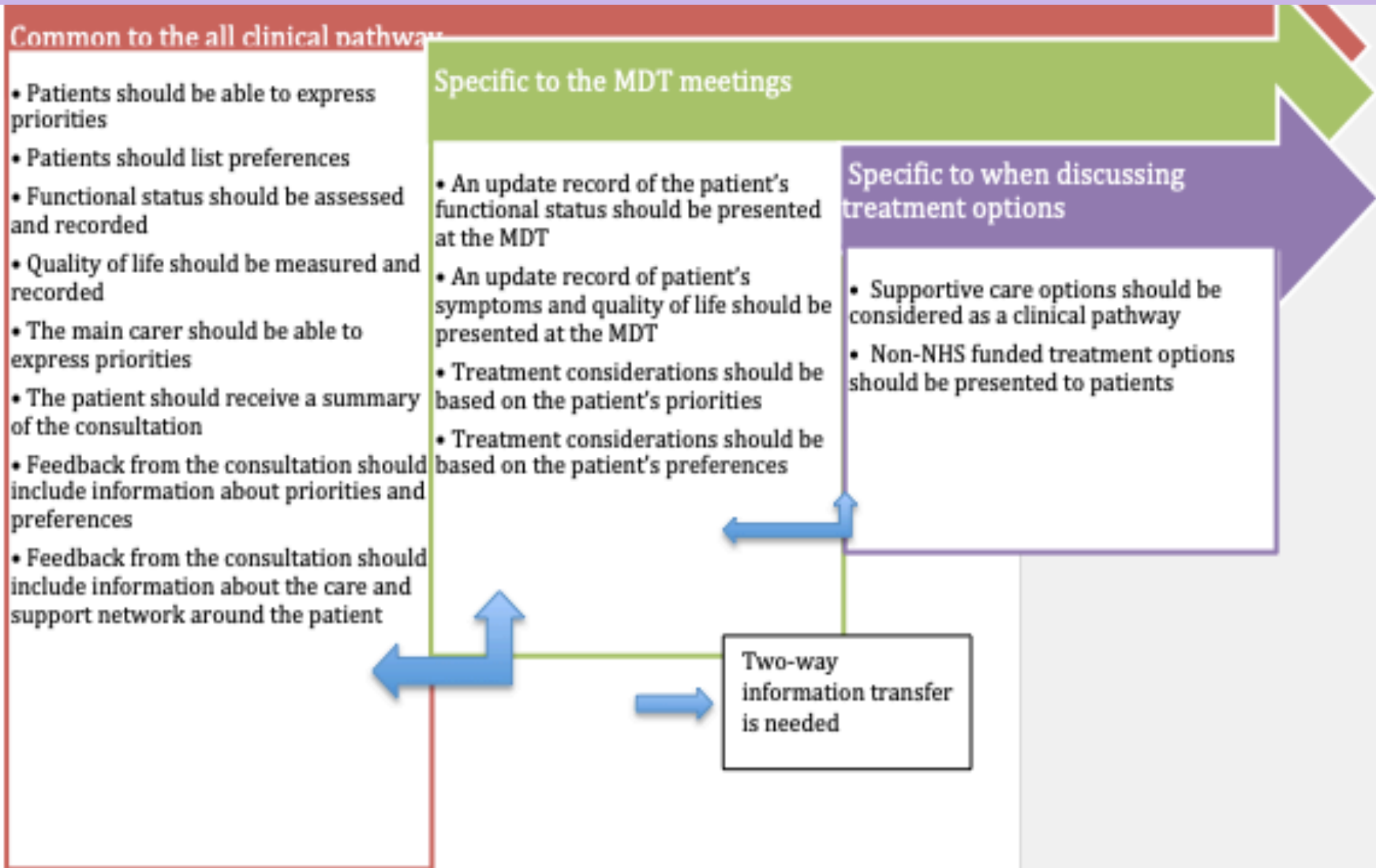
Specific to the MDT meetings

- An update record of the patient's functional status should be presented at the MDT
- An update record of patient's symptoms and quality of life should be presented at the MDT
- Treatment considerations should be based on the patient's priorities
- Treatment considerations should be based on the patient's preferences

Specific to when discussing treatment options

- Supportive care options should be considered as a clinical pathway
- Non-NHS funded treatment options should be presented to patients

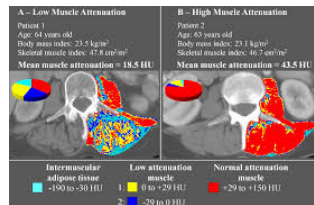
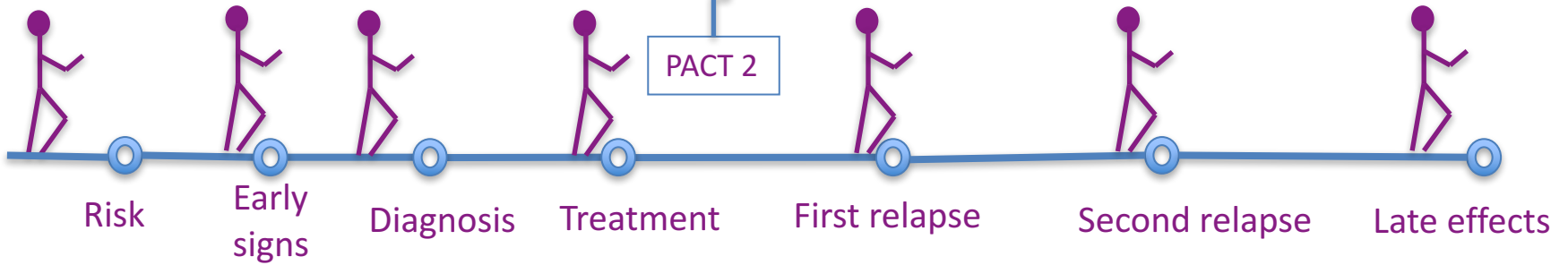
Two-way information transfer is needed



Future plans: PACT 2 and Integrated oncology



Mediated conversations



Effects of treatment

Functional resilience



Thank you

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