

NETHERLANDS
CANCER
INSTITUTE
ANTONI VAN LEEUWENHOEK



FINDINGS FROM THE INTERNATIONAL SARCOMA PRIORITY SETTING PARTNERSHIP SURVEY

GERARD VAN OORTMERSSEN
OLGA HUSSON



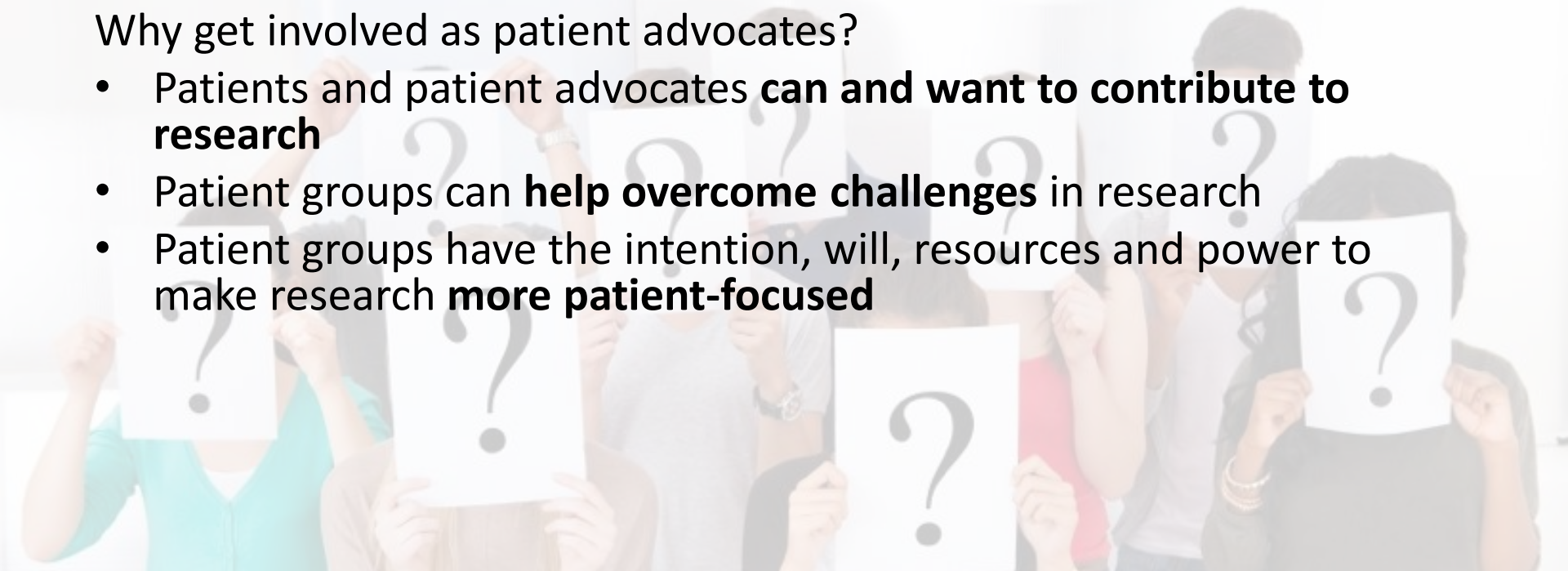
Why this all started

Our questions:

- What does sarcoma research decision making depend on?
- Does research in sarcomas answer actual patients' concerns and most important questions?
- Does sarcoma research follow a strategy and clear direction?

Why get involved as patient advocates?

- Patients and patient advocates **can and want to contribute to research**
- Patient groups can **help overcome challenges** in research
- Patient groups have the intention, will, resources and power to make research **more patient-focused**



Aims SPAEN project

- Examine how sarcoma patients and carers want to be involved in research
- Determine the research priorities of sarcoma patients and carers

Steps

Phase 1

- Step 1: Identification and invitation of potential partners
- Step 2: Awareness raising
- Step 3: Identifying evidence uncertainties & ways to involve patients and carers in research

Phase 2

- Step 4: Refining questions/uncertainties and ways to involve patients and carers in research
- Step 5: Prioritisation

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Survey - Section 1 Research priorities

What question(s) about “.....” would you like to see answered by research?

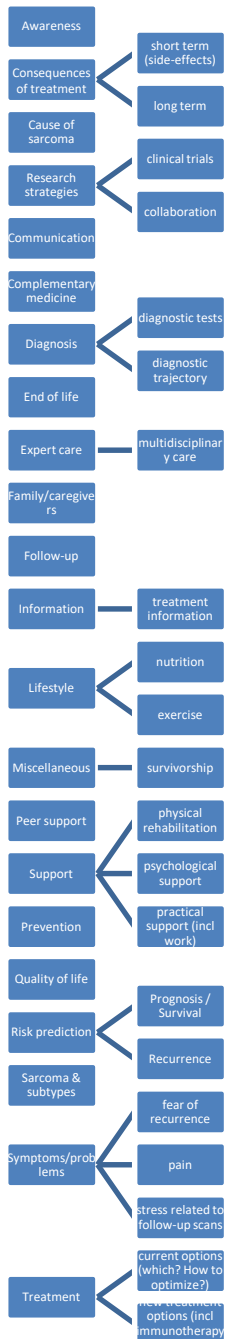
- diagnosis of sarcoma
- treatment(s)/treatment decisions
- support
- health-related quality of life issues and symptoms
- survivorship/ clinical follow-up would you like to see answered by research?
- end of life issues

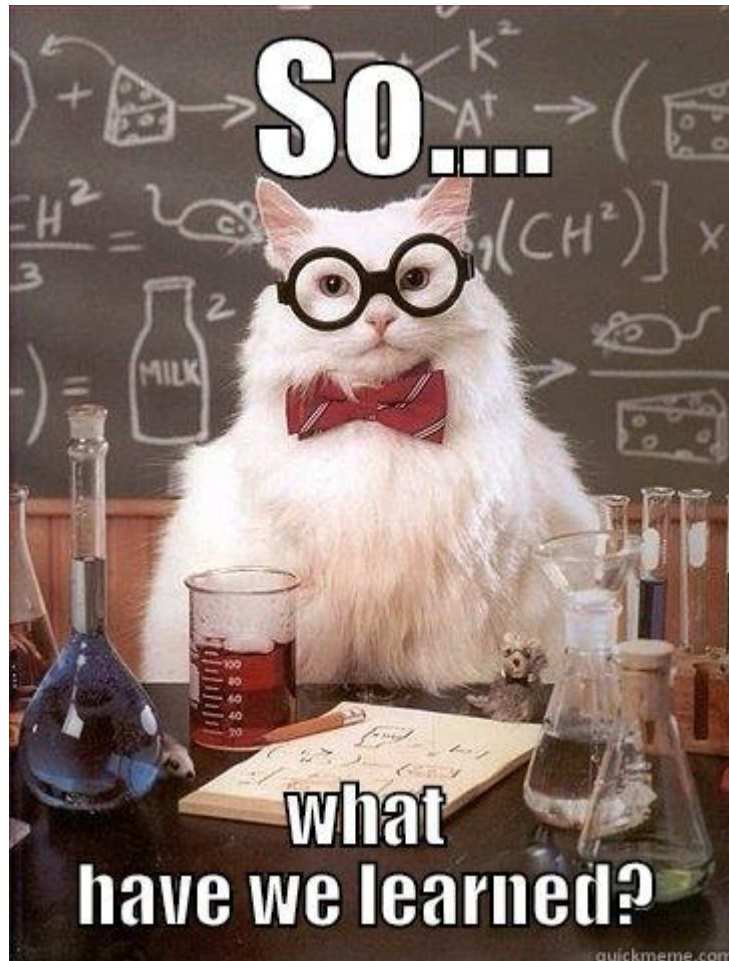
Results: Patient and carer characteristics

- Patients & carers (N=264)
- 76 male (29%); 183 female (69%); 5 missing
- Median age 53 years (range 19-82y); 5 missing
- 193 patients (73%); 50 carers (19%); 11 bereaved carers (4%); 8 other (3%); 2 missing
- 31 bone sarcoma (12%); 120 soft tissue sarcoma (46%); 71 GIST (27%); 20 desmoid fibromatosis (8%); 4 prefer not to say 4 (1%); 18 missing

Initial coding priorities

- 1175 different questions came up
- 22 main themes and 21 subthemes





- Quite some questions can be answered by better information provision!
Needs vs. topic for advocacy vs. research questions
- Too many themes

Different approach (1)

- Organising the questions according to CSO
 - International Cancer Research Partnership
Common Scientific Outline
 - Group the questions into themes to make them easier to review and discuss
 - Compare research funding allocation to the priorities identified by people with sarcoma, carers and healthcare professionals

CSO1: Biology;

CSO2: Etiology;

CSO3: Prevention;

CSO4: Early diagnosis, detection and prognosis;

CSO5: Treatment;

CSO6: Cancer control, survivorship, outcomes.

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CSO6.1 Patient Care and Survivorship issues

1. Research into patient centred outcomes
2. Quality of life

CSO2: Etiology

CSO2.1 Exogenous Factors in the Origin and Cause of Cancer

CSO2.2 Endogenous Factors in the Origin and Cause of Cancer

CSO2.3 Interactions of Genes and/or Genetic Polymorphisms with Exogenous and/or Endogenous Factors.

Different approach (2)

Make a clear distinction between:

R = research question

I = primarily need for information

A = advocacy topic: something that has to change

Results - example

CSO 4 Early Detection, Diagnosis, and Prognosis

A = topic for advocacy: something that has to change

A1 There is a great need for a better and faster diagnostic process for sarcoma (19, 20, 35, 61, 63, 68, 69, 70, 72, 75, 92, 94, 95, 97, 99, 104, 109, 113, 124, 136, 151, 154, 155, 159, 160, 161, 162, 164, 169, 171, 175, 203, 221, 222, 229, 237, 240).

- Desmoid fibromatosis (72, 75)
- GIST (92, 113)
- Leiomyosarcoma (63, 95)
- Low grade abdominal sarcoma (169)
- Low grade sarcoma (229)

A2 There is a need for quicker referral to sarcoma expertise centres (104, 161).

R = research question

R1 How often do misdiagnoses occur in sarcoma patients (129)?

R2 What is the difference between fibrosarcoma and osteosarcoma and how can be better differentiated in the diagnostic process (178)?

I = primarily need for information

I1 Why is it that the name/subtype of sarcoma is sometimes unknown (247)?

I2 How is it possible that a GIST of over 10 centimetres was asymptomatic (235)?

I3 Is GIST still considered incurable or not and when is someone considered cured (142)?

I4 Why are elaborate blood tests not more often used in diagnoses and follow-up of sarcoma (137, 149)?

First example of usefulness

- Subset of leiomyosarcoma patients
- NLMSF -SPAEN Round Table
- Input for grant reviewing and unmet needs paper

Diagnosis

- Need for earlier detection
- Develop new techniques (blood test, imaging)
- Distinguish benign/malignant (uterine s.)
- Symptoms and triggers?
- Educate GP's

Treatment

- Better treatment badly needed
- Research on innovative treatments
 - Immunotherapy
 - Personalised medicine
 - Multi-modal therapies
 - Sequencing of treatments
 - Balancing risk-benefit, survival vs. QoL
 - Distinction between stable disease and progression
 - Complementary treatments
 - Joint decision making: better info

Support

- Better support during entire patient journey
- Case management
- What can I do myself? Life style, food, exercise...
- Physio, recovery care
- Peer support

Quality of life

- Coping with being a sarcoma patient
- Accepting changes in body image
- Physical performance
- Depression, anxiety, emotions
- Managing side effects

Survivorship

- Patient or "healed"? Distinction not clear
- Optimise follow-up (precision, interval)
- Late effects
- Research specific diets for survivors
- "Whole health" care advice

End of life

- What will happen in final phase
- Can I die at home
- Information for carers and family to provide adequate support

Next steps

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Questions

