Beneath the surface:
The psychosocial impacts of precision medicine

Prof Claire Wakefield
Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children’s Hospital
School of Women’s and Children’s Health, UNSW Sydney
@cewakefield
### Background

<table>
<thead>
<tr>
<th>Australian context</th>
<th>Cure rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>950 new diagnoses/year</td>
<td>&gt;80% survival</td>
</tr>
<tr>
<td>60% treated on at least one clinical trial</td>
<td></td>
</tr>
</tbody>
</table>
Background

Cure rate

>80% survival

Remains low for high risk children (relapse, brain and solid tumours)

Advances

~10% germline mutation

Novel technologies

Precision medicine

WGS

In vitro/in vivo drug screening

Australian context

950 new diagnoses/year

60% treated on at least one clinical trial

Novel technologies~10% germline mutation

Precision medicine

WGS

In vitro/in vivo drug screening

Cure rate

>80% survival

Remains low for high risk children (relapse, brain and solid tumours)

Australian context

950 new diagnoses/year

60% treated on at least one clinical trial
The promise of precision medicine

- Reduced side effects
- Improved survival
The promise of precision medicine

CARE
- Reduced side effects
- Improved survival

UKNOWNS
- Impact on child
- Impact on parents
- Impact on professionals
### Evidence from other studies

<table>
<thead>
<tr>
<th>Adult cancer</th>
<th>Parents</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary reason to enrol: hope; not altruism</td>
<td>Unrealistic expectations?</td>
<td>Consent?</td>
</tr>
<tr>
<td>Therapeutic misconceptions?</td>
<td>Willing to try anything?</td>
<td>Understanding?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Long term outcomes?</td>
</tr>
</tbody>
</table>
PRISM steps and stakeholders

- Patients
- Parents
- HCPs
- Community
Introduction: Our studies

- PRISM-Impact
  - Impact on AYAs

- Avatar acceptability

- GenPact

Review 1: HCPs' perceptions

Review 2: Patients, Parents, HCPs, Community
Cancer-related genetic testing and personalised medicine for adolescents: A narrative review of impact and understanding

Vetsch J., Wakefield C.E., Warby M., Tucker K., Patterson P., McGill B., Metcalfe A., Cohn R.J.
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Sparse data: 9 studies
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Benefits

- Future planning
- No clear increased distress

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Harms
- Cancer-specific distress
- Worries about future health

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Benefits
- Future planning
- No clear increased distress

Harms
- Cancer-specific distress
- Worries about future health

Genetic literacy
- Limited

Sparse data: 9 studies
Advantages

- Aid with treatment-related decisions
- Somatic testing
  - Info on prognosis / risk
- Professional satisfaction
  - Germline testing
    - Advanced understanding of causes and pathways
    - Understand familial risk

23 studies, 4393 HCPs

Healthcare professionals’ attitudes toward cancer precision medicine: A systematic review


Advantages

- Aid with treatment-related decisions

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**Advantages**
- Aid with treatment-related decisions

**Somatic testing**
- Info on prognosis / risk
- Professional satisfaction

**Germline testing**
- Advanced understanding of causes and pathways
- Understand familial risk

23 studies, 4393 HCPs
Healthcare professionals’ attitudes toward cancer precision medicine: A systematic review


Disadvantages
- Potential over-reliance/overuse
- High costs
- Future health insurance impact

Lack of:
- Evidence and guidelines
- Confidence making treatment recommendations
- Access to testing

23 studies, 4393 HCPs
Healthcare professionals’ attitudes toward cancer precision medicine: A systematic review


- Comfortable to disclose actionable results
- More reluctant to disclose VUS, non-treatable conditions
- Germline results: Can distract from treatment, increased psychosocial impacts

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- More reluctant to disclose VUS, non-treatable conditions
- Germline results: Can distract from treatment, increased psychosocial impacts

Attitudes

Intentions

- Positive attitude toward future use

23 studies, 4393 HCPs
‘GenPact’: The psychosocial impact of genetic testing in childhood cancer

Cancer-related genetic testing can...

- Inform treatment
- Guide follow up/surveillance
- Prompt testing in family members
Cancer-related genetic testing can...

- Inform treatment
- Guide follow up/surveillance
- Prompt testing in family members

Unknown

Implications for individual and family
Who

- 35 families of children (≤18yo) at time of referral to genetic services
- Kids Cancer Centre /
  Hereditary Cancer Clinic, Randwick

Aims

Explore patients' and parents’:

- Understanding
- Information needs
- Psychosocial impact
- Satisfaction with genetic services
THEMES:
Referrals taken up with little hesitation
Does the referral fit the family health ‘narrative’?

Personal genetics beliefs and reaction to referral
THEMES:
- Referrals taken up with little hesitation
- Does the referral fit the family health ‘narrative’?

Experiences of genetic counselling and testing

Personal genetics beliefs and reaction to referral

THEMES:
- Satisfied with quality of care
- Few regrets
- ‘Knowledge is power’
THEMES:
Referrals taken up with little hesitation
Does the referral fit the family health ‘narrative’?

Experiences of genetic counselling and testing

THEME:
Complex emotions: guilt

Personal genetics beliefs and reaction to referral

THEMES:
Satisfied with quality of care
Few regrets
‘Knowledge is power’

Impact of and coping with results
THEMES:
- Referrals taken up with little hesitation
- Does the referral fit the family health ‘narrative’?

Experiences of genetic counselling and testing

THEME:
Complex emotions: guilt

Longer-term information and support needs

THEMES:
- Satisfied with quality of care
- Few regrets
- ‘Knowledge is power’

Personal genetics beliefs and reaction to referral

Impact of and coping with results

THEMES:
- Need information, longer-term support
  - I don’t know/ I’ve forgotten
  - Wanting reassurance, to stay connected
  - Life transitions

THEMES:
- Complex emotions: guilt
  - Satisfaction with quality of care
  - Few regrets
  - ‘Knowledge is power’

UNSW Australia
Next steps

- Families enrolled in WGS research trial (GenSeq)
- All newly diagnosed paediatric cancers
- Sydney Children’s Hospital / Children’s Hospital Westmead

Aims

Prospectively assess families’:

- Understanding
- Information needs
- Expectations and concerns
- Psychosocial impact
- Communication preferences
The avatar acceptability study:
A multiperspective cross-sectional study evaluating the acceptability of using patient-derived xenografts to guide personalised cancer care in Australia and New Zealand

Patient-derived xenografts (PDX) involve engrafting tumours directly from a patient into immune deficient mice.
Patient-derived xenografts

**RESEARCH**
- Develop new therapies
- Drug sensitivity
- Preclinical drug

**TRANSITION**

**CARE**
- Personalised medicine
- Improved outcomes
My genes are in mice, and not in the basal way
that Man's old genes are in the Beasts.

My doctors split my tumors up and scattered them
into the bones of twelve mice. We give

the mice poisons I might, in the future, want
for myself. We watch each mouse like a crystal ball.

I wish it was perfect, but sometimes the death we see
doesn't happen when we try it again in my body.

My tumors are old, older than mice can be.
They first grew in my flank, a decade ago.

Then they went to my lungs, and down my femurs,
and into the hives in my throat that batch white cells.

The mice only have a tumor each, in the leg.
Their tumors have never grown up. Uprooted

and moved. Learned to sleep in any bed
the vast body one down. Before the tumors can spread,

they bust open the legs of the mice. Who bleed to death.
Next time the doctors plan to cut off the legs

in the nick of time so the tumors will spread.
But I still have both my legs. To complicate things further,

mouse bodies fight off my tumors. We have to give
the mice arms so they'll harbor my genes.

I want my mice to be just like me. I don't have any children.
I named them all Max. First they were Max 1, Max 2,

but now they're all just Max. No playing favorites.
They don't know they're named, of course.

They're like children you've traumatized
and tortured so they won't let you visit.

I hope, Maxes, some good in you is of me.
Even my suffering is good, in part. Sure, I swell

with rage, fear—the stuff that makes you see your tail
as a bar on the cage. But then the feelings pass.

And since I do absolutely nothing (my pride, like my fur,
all gone) nothing happens to me. And if a whole lot

of nothing happens to you, Maxes, that's peace.
Which is what we want. Trust me.

Max Ritvo was awarded a 2014 Poetry Society of America Chapbook Fellowship for "Aeon." His
debut collection, "Four Reincarnations," will be published this October.
Avatar Study: Design

**Stage 1 pilot, N=24**
- Exploratory interviews
- Identify key benefits and concerns
- 24 participants (16 survivors, 8 parents)

**Stage 2 study, N=1,550**
- 1,298 adults
  - 648 survivors of child and adult cancers
  - 650 community adults
- 252 parents
  - 48 parents of survivors
  - 204 community parents
Avatar Study: Design

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- Exploratory interviews
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Domains of Interest
- Acceptability
- Decisional balance
- Implementation
Avatar Study: Results

Most influential in cancer (1 – 7 rating of influence)

Benefits

1. Improve survival
2. Help future research
3. Avoid wrong drugs
4. Faster recovery
5. Fewer side effects
6. Increased confidence
7. Reassurance you’ve tried everything

Concerns

1. Recommended drug unavailable/expensive
2. Difficult to switch treatment
3. Might not work
4. Time delay
5. Recommended drug different/incompatible
6. May not find effective drug
7. Harms animals

UNSW AUSTRALIA
Avatar Study: Results

Most influential in community samples (1 – 7 rating of influence)

Benefits
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7. Harms animals
Avatar Study: Results

Decisional balance
Avatar Study: Results

Decisional balance

>1: Leaning towards (mean benefits score outweighs mean concerns score)
=1: Decisional equivalence (mean benefits score equals mean concerns score)
<1: Leaning towards (mean concerns score outweighs mean benefits score)
Avatar Study: Results

Predictors

**Adults**
- Survivor
- Male
- Older
- Higher income

**Parents**
- Parent of survivor
- Mother
- Higher income

Higher decisional balance
Avatar Study: Results

Implementation
Turnaround time

Maximum time willing to wait

- Community adults
- Survivors

Maximum time willing to wait

- Community parents
- Survivors' parents

Cumulative Frequency %
Avatar Study: Results

Implementation
Turnaround time

Predictors

**Adults**
- Survivor
- Male
- Higher income

**Parents**
- Parent of survivor
- Fathers
- Higher income

**Maximum time willing to wait**

- **Community adults**
- **Survivors**

- **Communication parents**
- **Survivors’ parents**

Willing to wait longer
Avatar Study: Results

Implementation
Willingness to pay

Maximum amount willing to pay

Cumulative frequency %

0 10 20 30 40 50 60 70 80 90 100

Up to $100 Up to $500 Up to $1K Up to $5K Up to $10K Up to $20K Up to $30K Up to $40K Up to $50K

Maximum amount willing to pay

Cumulative frequency %

0 10 20 30 40 50 60 70 80 90 100

Up to $100 Up to $500 Up to $1K Up to $5K Up to $10K Up to $20K Up to $30K Up to $40K Up to $50K

- Community adults
- Survivors

- Community parents
- Survivors' parents
Avatar Study: Results

Implementation
Willingness to pay

“I would rob a bank, it would not matter”
Avatar Study: Results

Implementation
Willingness to pay

Predictors

Adults
- Survivor
- Male
- Higher income

Parents
- Parent of survivor
- Higher income

“I would rob a bank, it would not matter”
Avatar Study: Results

“I’m an animal lover [but].. When it comes to my son or a mouse, it’s just a no-brainer”

“If you look at it in an ethical vacuum it’s one thing, but if you look at it as your own child, your flesh and blood dying before you, you’re going to make different choices”

“If it’s one child to ten mice vs one child to a thousand mice, it rapidly becomes a very complex question....You’ve got to draw the line somewhere”
Avatar Study: Results

Implementation

Animals used
Avatar Study: Results

Implementation
Animals used

Predictors

Adults
- Survivor

Survivors
- Parent of survivor
- Higher education

Willing to use more
Avatar Study: Conclusions

Acceptability

PDX acceptable (despite lack of strong efficacy data)

Useful for future consents

Expectations largely align with likely service (education about wait time valuable)

Outcomes

Interdisciplinary work is great fun!
PRISM-Impact

2015

Zero Childhood Cancer Program launch

The Sydney Children’s Hospitals Network
Children’s Cancer Institute

2016

Pilot Study

28 children from The Sydney Children’s Hospitals Network with high risk or relapsed cancer

2017 - 2019

Clinical Trial

400 children across Australia with high risk or relapsed cancer

2020

Better outcomes with less side effects

Available to all children with high risk cancer in all children’s hospitals nationally

Ongoing analysis of clinical, genetic & biological data
Children’s Cancer Institute
PRISM

T0: 2-4 weeks after enrolment

T1: 2-8 weeks after results delivery

T2-5: Annually

Annual clinician and scientist interviews
Objectives

**PRISM**

To determine:
- % of patients receiving personalised medicine in relevant timeframe

**PRISM-IMPACT**

To understand:
- Hopes
- Concerns
- Psycho-social impact
- Satisfaction
- Understanding

**Participants**

- Parents (bereaved parents recontacted > 6months)
- Patients >12 years
- Clinicians (physicians, geneticists, genetic counsellors) and scientists
124 PRISM families

71 PRISM-Impact families
(57% response rate)
PRISM-Impact: Families

124 PRISM families

71 PRISM-Impact families
(57% response rate)

T0: 47 families
63 parents
15 adolescents

T1: 10 families
15 parents
2 adolescents

8 children deceased
## PRISM-Impact: Families

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Parents (n=63)</th>
<th>Adolescents (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (participant)</td>
<td>40.6 years (range=25-59)</td>
<td>14.9 years (range=12-21)</td>
</tr>
<tr>
<td>Mean age (child)</td>
<td>8.46 years (range=0-17)</td>
<td>n/a</td>
</tr>
<tr>
<td>Gender</td>
<td>41 mothers (65.1%) 22 fathers (34.9%)</td>
<td>11 females (73.3%) 4 males (26.7%)</td>
</tr>
<tr>
<td>Marital status</td>
<td>92% married</td>
<td>n/a</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>41.3% CNS 34.9% sarcoma 4.8% haematologic 19.0% others</td>
<td>66.7% sarcoma 13.3% CNS 13.3% haematologic 6.7% others</td>
</tr>
</tbody>
</table>
PRISM-Impact: Clinicians and scientists

- 8 sites
- 81 invited
- 62 opted in (77% response rate)
- 54 interviewed
# PRISM-Impact: Clinicians and scientists

<table>
<thead>
<tr>
<th>Demographics</th>
<th>HCPs (n=54)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professions</td>
<td>31 paediatric haematologists/oncologists</td>
</tr>
<tr>
<td></td>
<td>1 paediatric oncology research fellow</td>
</tr>
<tr>
<td></td>
<td>1 clinical geneticist</td>
</tr>
<tr>
<td></td>
<td>1 genetic counsellor</td>
</tr>
<tr>
<td></td>
<td>16 scientists</td>
</tr>
<tr>
<td>Mean age</td>
<td>44.17 years (range=25-73)</td>
</tr>
<tr>
<td>Gender</td>
<td>28 females</td>
</tr>
<tr>
<td></td>
<td>26 males</td>
</tr>
<tr>
<td>Average years experience</td>
<td>16.07 years (range=1-45)</td>
</tr>
<tr>
<td>Clinicians’ dedicated time to research</td>
<td>25.43% (range = 0%-80%)</td>
</tr>
<tr>
<td>Scientists’ dedicated time to the study</td>
<td>68.46% (range = 10%-100%)</td>
</tr>
</tbody>
</table>
PRISM-Impact: Reasons for enrolment

Parents

~30% had multiple reasons

“"To increase the likelihood of a cure for my daughter’s relapse."" Mother of 9yo girl

“To give my daughter every possible chance to survive...and to help any future cancer patients... Also to help researchers get more knowledge of this type of cancer.”

Mother of 2yo girl

<table>
<thead>
<tr>
<th></th>
<th>Proportion (%)</th>
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<tbody>
<tr>
<td>Personal benefit</td>
<td>70</td>
</tr>
<tr>
<td>Future patients</td>
<td>30</td>
</tr>
<tr>
<td>Recommended by oncologist</td>
<td>20</td>
</tr>
<tr>
<td>Research/science</td>
<td>10</td>
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PRISM-Impact: Reasons for enrolment

Parents

<table>
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<th>Reason</th>
<th>Proportion (%)</th>
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<td>Personal benefit</td>
<td>20</td>
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<td>Research/science</td>
<td>35</td>
</tr>
<tr>
<td>Felt obliged</td>
<td>5</td>
</tr>
</tbody>
</table>

“I understand the importance of having a wholistic understanding of the impact of a study on the person.”

Mother of 2yo girl
PRISM-Impact: Concerns at enrolment

Parents' concerns

I am concerned that...

- Somatic results would be stressful or cause anxiety
- Germline results would be stressful or cause anxiety
- Information about my family would be stressful or cause anxiety
- My child's cancer is less treatable or more aggressive
- Results may take a long time to come back

* Significantly different

Extremely true

Not at all
Somatic results will cause anxiety
Germline results will cause anxiety
Information about family will cause anxiety
May learn the cancer is less treatable than expected
Results may take a long time

Clinicians’ and scientists’ concerns

I am concerned that...

Extremely true
Not at all true
PRISM-Impact: Who will benefit?

<table>
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<tr>
<th>Group</th>
<th>Professionals (n=54)</th>
<th>Adolescents (n=15)</th>
<th>Parents (n=63)</th>
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<tbody>
<tr>
<td>Patients</td>
<td>10 (18.5%)</td>
<td>5 (33.3%)</td>
<td>21 (33.3%)</td>
</tr>
<tr>
<td>Parents and family members</td>
<td>7 (13.0%)</td>
<td>0 (0%)</td>
<td>1 (1.6%)</td>
</tr>
<tr>
<td>Future patients</td>
<td>19 (35.2%)</td>
<td>8 (53.3%)</td>
<td>24 (38.1%)</td>
</tr>
<tr>
<td>Doctors</td>
<td>2 (3.7%)</td>
<td>0 (0%)</td>
<td>2 (3.2%)</td>
</tr>
<tr>
<td>Scientists</td>
<td>11 (20.4%)</td>
<td>0 (0%)</td>
<td>10 (15.9%)</td>
</tr>
<tr>
<td>Others</td>
<td>1 (1.9%)</td>
<td>1 (6.7%)</td>
<td>0 (0%)</td>
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Who do you think will benefit the most from PRISM?
Perceptions about PRISM information, understanding and expectations
### PRISM-Impact: Perceptions

#### Families’ feedback about information sheet and consent form

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<tr>
<td>From cover to cover</td>
<td>1 (6.7%)</td>
<td>17 (27.0%)</td>
</tr>
<tr>
<td>Quite thoroughly</td>
<td>2 (13.3%)</td>
<td>19 (30.2%)</td>
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<tr>
<td>Just the parts I felt were relevant</td>
<td>2 (13.3%)</td>
<td>9 (14.3%)</td>
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<td>Briefly</td>
<td>6 (40.0%)</td>
<td>12 (19.0%)</td>
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<td>I didn’t read the information</td>
<td>4 (26.7%)</td>
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<td>3 (20.0%)</td>
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<td>Just right</td>
<td>7 (46.7%)</td>
<td>49 (77.8%)</td>
</tr>
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<td>5 (33.3%)</td>
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**Families’ feedback about information sheet and consent form**

*“It felt overwhelming to read and process on the first go as there was a lot of information.”*  
Mother, 2yo girl

**Suggestions:**
- Flowchart, diagrams, pictures
- Simplify language
Parents’ subjective understanding

How well do you understand....

- What the researchers are trying to find out in PRISM
- Procedures my child will undergo
- Possible risks and discomforts of participating
- Possible benefits to my child of participating in PRISM
- Benefits to future patients
- Alternatives to PRISM
- Effect of PRISM on the confidentiality of my child’s records
- Who to contact if I have questions or concerns
- That participation in PRISM is voluntary

Overall, how well did you understand PRISM when you signed the consent form?

Very well
Not at all
### Parents’ understanding of PRISM

#### PRISM-Impact: Perceptions

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<tr>
<th>Understanding</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>All the treatments and procedures are <strong>standard</strong></td>
<td>11 (17.5%)</td>
<td>26 (41.3%)</td>
<td>24 (38.1%)</td>
</tr>
<tr>
<td>The <strong>main</strong> reason this study is being done is to improve my child’s treatment.</td>
<td>19 (30.2%)</td>
<td>12 (19.0%)</td>
<td>30 (47.6%)</td>
</tr>
<tr>
<td>PRISM treatment recommendations are <strong>certain to be effective</strong></td>
<td>22 (34.9%)</td>
<td>25 (39.7%)</td>
<td>14 (22.2%)</td>
</tr>
<tr>
<td>My child will have to remain in PRISM</td>
<td>45 (71.4%)</td>
<td>8 (12.7%)</td>
<td>8 (12.7%)</td>
</tr>
</tbody>
</table>
## PRISM-Impact: Perceptions

<table>
<thead>
<tr>
<th>Parents’ expectations of PRISM</th>
<th>Very likely to somewhat likely</th>
<th>Very unlikely to somewhat unlikely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likelihood of receiving <strong>some results</strong> from the PRISM study</td>
<td>57 (93.4%)</td>
<td>4 (6.6%)</td>
</tr>
<tr>
<td>Likelihood of receiving a <strong>new treatment option</strong></td>
<td>43 (70.5%)</td>
<td>18 (29.5%)</td>
</tr>
<tr>
<td>Likelihood of finding a <strong>germline mutation</strong></td>
<td>39 (65.0%)</td>
<td>21 (35.0%)</td>
</tr>
</tbody>
</table>
How do things change over time?
I hope PRISM will...

**PRISM-Impact: Temporal changes**

- **Increase my child's chance of being cured**
- **Help find cures for future patients**

- **Not at all true**
- **Extremely true**

---

**n=15 parents**
I hope PRISM will...

**PRISM-Impact: Temporal changes**

- **increase my child's chance of being cured**
- **help find cures for future patients**
- **provide information about my child's cancer**
- **teach me about my child's genes**

- **1** Extremely true
- **2** Not at all true

**n=15 parents**
Parents’ satisfaction over time

PRISM-Impact: Temporal changes

Parents’ satisfaction over time

Completely satisfied
Not at all

T0      T1

Mother  Father
PRISM-Impact: Temporal changes

Parents’ regret at T1

Graph showing the regret levels for parents at time point T1.
What is the impact of PRISM?
Do you have the feeling that being part of PRISM has made it **harder to cope** with (you/your child) being sick?

**PRISM-Impact: Impact**

<table>
<thead>
<tr>
<th>Parents</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>53 (84.1%)</td>
<td>4 (6.3%)</td>
<td>1 (1.6%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adolescents</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>14 (93.3%)</td>
<td>1 (6.7%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>
Do you have the feeling that being part of PRISM has made it **easier to cope** with (you/your child) being sick?

### PRISM-Impact: Impact

#### Parents

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling easier to cope</td>
<td>24 (38.1%)</td>
<td>16 (25.4%)</td>
<td>11 (17.5%)</td>
<td>4 (6.3%)</td>
<td>2 (3.2%)</td>
</tr>
</tbody>
</table>

#### Adolescents

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling easier to cope</td>
<td>9 (60.0%)</td>
<td>1 (6.7%)</td>
<td>3 (20.0%)</td>
<td>2 (13.3%)</td>
</tr>
</tbody>
</table>
Clinician and scientist experiences
PRISM-Impact: Clinicians and scientists

Themes

• Better outcomes
• Access to additional treatments
• Tried everything

Advantages

Scientists

Clinicians
PRISM-Impact: Clinicians and scientists

**Themes**
- Better outcomes
- Access to additional treatments
- Tried everything

**Advantages**
- "tailored treatments for each patient"
- "you might not be able to cure them...but you may be able to extend their life and give them a better quality of life with their families."
- "...cutting edge, state-of-the-art profiling of their tumours, they don’t have to try send it off to these private companies to do it."
- "a patient...started with one of these target drugs...she’s improved dramatically."

Scientists

Clinicians
PRISM-Impact: Clinicians and scientists

**Themes**
- Better outcomes
- Access to additional treatments
- Tried everything

**Advantages**
- "...access to treatments that they wouldn’t otherwise have access to."
- "...we can potentially offer some sort of alternative to what would otherwise be virtually no option."
- "...access to potentially curative treatment..."
- "...increased treatment options..."
PRISM-Impact: Clinicians and scientists

Themes
• Chance of cure
• Access to additional treatments
• Tried everything

Advantages

“...not leaving any stone unturned, of being able to feel like that they’ve explored all the options.”

“...knowing that everything is being done.”

Scientists

Clinicians
PRISM-Impact: Clinicians and scientists

**Challenges and concerns**

**Themes**
- Difficulty accessing drugs
- Time pressure
- False hope
- Use of resources
- Poor biopsy quality
PRISM-Impact: Clinicians and scientists

**Challenges and concerns**

**Themes**
- Difficulty accessing drugs
- Time pressure
- False hope
- Use of resources
- Poor biopsy quality

**Scientists**

“...the company said ‘no, we can’t give her the drugs because she’s on steroids’ and she passed away...”

“if we had access to all the drugs that we wanted, maybe it would be different.”

**Clinicians**

“...getting access to the drugs remains the big challenge.”

“...there is a drug available but we can’t get the drug.”
PRISM-Impact: Clinicians and scientists

Challenges and concerns

- Difficulty accessing drugs
- Time pressure
- False hope
- Use of resources
- Poor biopsy quality

Scientists

“...the longer we take to do anything, the smaller proportion of patients you can benefit.”

“...we’re in real-time now... what happens if we don’t meet that turnaround time?”

Clinicians

“It’d be great if we did all that in 3 to 4 weeks but probably it’s gonna be a little bit longer”

“I think it is about timing and sometimes we don’t have the luxury of time to wait”
Themes

- Difficulty accessing drugs
- Time pressure
- False hope
- Use of resources
- Poor biopsy quality

Challenges and concerns

- "...it may provide false hope."
- "...not having a clinical outcome for them."
- "...false hope that it might give a cure."
- "...misconceptions of how much personalised medicine can offer."
PRISM-Impact: Clinicians and scientists

Themes
• Difficulty accessing drugs
• Time pressure
• False hope
• Use of resources
• Poor biopsy quality

Challenges and concerns

“...extravagantly expensive on a per patient basis.”

“...very complex and takes a lot of time and a lot of resources.”
PRISM-Impact: Clinicians and scientists

**Themes**
- Difficulty accessing drugs
- Time pressure
- False hope
- Use of resources
- Poor biopsy quality

**Challenges and concerns**

"...we don’t get a good quality of samples."

"...the samples that we get are...not high quality enough."

"...get enough quality samples that will actually get the information that you actually want."
PRISM-Impact: Clinicians and scientists

Multi-disciplinary tumour board

Themes
- Technical difficulties
- Clinician reservations
- Logistics
PRISM-Impact: Clinicians and scientists

Themes

- Technical difficulties
- Clinician reservations
- Logistics

Multi-disciplinary tumour board

Scientists

“There are some technical challenges, it can be better. It can be done if we have a little bit better technology available.”

Clinicians

“...the audio quality can be quite poor.”
PRISM-Impact: Clinicians and scientists

Scientists

“I find the clinicians more conservative than I ever thought they would be...the adversity to recommend something that was unproven is much higher than I thought it would be.”

Clinicians

“It’s a little more conservative... instead of taking some of our recommendations on board, they rather just stick to the traditional first.”

Multi-disciplinary tumour board

Themes
- Technical difficulties
- Clinician reservations
- Logistics
PRISM-Impact: Clinicians and scientists

Themes
- Technical difficulties
- Clinician reservations
- Logistics

Multi-disciplinary tumour board

"...timing of the...meeting has just been a nightmare for us."

"...interferes with another meeting we have."
Families

- Hope for child balanced with hope for future patients
- High perceived understanding, with gaps
- Minority read everything
- Low perceived burden
- Few regrets

Clinicians and scientists

- See value in precision medicine
- Some concerns, negative experiences
- Strong collaborative approach
PRISM-Impact: Significance

- Understanding needs and concerns of stakeholders
- Identify implementation barriers

Next steps

- Address concerns early, devise solutions
- Develop resources for (e.g. decision aid)
- Address access/inequity- launch of economic costs study
Participants TARGET / PRISM
All investigators and funding bodies