“The view from here”
patient perspectives on the response to problem metal-on-metal hips

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Background

- Small, pilot project
- Map patients’ experiences living with metal on metal hip failure
- Focus groups – 36 well-informed patients & their families
- Online survey – 164 responses
Country of residence

- Great Britain: 77.5%
- USA: 5.6%
- Ireland: 4.4%
- Australia: 3.8%
- Denmark: 3.1%
- Other: 5.6%
Age/gender

- Age groups: 0-35, 36-45, 46-55, 56-65, 66-75, 75+
- Gender: Male (M), Female (F)

- u35: 3 M, 2 F
- 36-45: 7 M, 7 F
- 46-55: 20 M, 18 F
- 56-65: 36 M, 19 F
- 66-75: 27 M, 13 F
- 75+: 1 M, 7 F

The chart shows the distribution of age and gender across different age groups.
Type of hip replacement

33% bilateral, 66% unilateral
67% had/planned revision
2c) What were your expectations about the hip replacement?

<table>
<thead>
<tr>
<th>I expected ...</th>
<th>Positive %</th>
<th>Neutral %</th>
<th>Negative %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Return of mobility</td>
<td>92.7</td>
<td>5.7</td>
<td>1.6</td>
</tr>
<tr>
<td>Free from pain</td>
<td>98.4</td>
<td>0.8</td>
<td>0.8</td>
</tr>
<tr>
<td>Return of activity</td>
<td>88.5</td>
<td>9.8</td>
<td>1.6</td>
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High trust in device/procedure/healthcare
Popular recognition of success builds appeal
Drives innovation
Impact of failure - after

3a) What are the most significant impacts the metal-on-metal hip implant has had on your life?

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<thead>
<tr>
<th>Positive</th>
<th>Neutral</th>
<th>Negative</th>
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<tbody>
<tr>
<td>20.9%</td>
<td>1.1%</td>
<td>77.9%</td>
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</table>

3b) Do you have concerns about your metal-on-metal hip replacement(s)?

<table>
<thead>
<tr>
<th>Positive</th>
<th>Neutral</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.0%</td>
<td>2.4%</td>
<td>91.6%</td>
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</table>
What it means for patients

- Poor mobility, pain
- Social and family lives disrupted
- Job loss/under threat
- Loss of confidence and independence
- Social isolation
- Distress, anxiety, depression and attempted suicide
Consequences

“I was never able to walk again, I lost my work, independence, my confidence, my ability to leave my home I was in more pain than pre op my mobility was significantly decreased”

“I am now on medication for anxiety, nobody can give me information of what can be done”
Consequences

“spoilt my valuable retirement time, after working hard since 15 yrs old, and just finished my working life at the age of 65, 50 yrs non stop. ...made me feel very old, and worst of all dependent for the first time in my life on other people, i also worry, even after revision surgery, about possible future problems”
Focus group questions

- Who do you think is responsible for ‘what has happened’ with metal-on-metal hips?
- Who should be responsible for making sure the issues you have just discussed don’t happen again?
- Tell us how this has affected your trust in medicine?
Focus group results

- (lack of) response to problems more of an issue than the failure itself
  - who is responsible for evaluating and responding to evidence on failures?
  - don’t see concerted action
  - or clear responsibility
  - justice – “if no-one is responsible then something is very wrong – ethically and morally”
Focus group comments

“It seems vague doesn’t it – the responsibility? Did they pass them or…..? and then there is this Joint Registry…..they just seem to collect the information and don’t seem to do anything with it.”

“There’ll always be problems and errors made in whatever field of you know, medicine, design, engineering, they’re always gonna be errors and it’s how you cope with those errors and how you stand up to handling those errors.”
Survey – what now?

5a) What do you think should be done now and in the future to improve the service for people undergoing joint replacement?

- Testing of implants
- Communication patient/surgeon, give patients choice, more information to patients (pre & post), monitoring
- Better regulation
- Moratorium on MOM

“I was extremely disappointed to hear that these joints were not tested as drugs are tested. … If this had been so this problem would not have happened.”
5b) What do you think engineers & health professionals can do to help here?

“Ensure adequate testing is done and make that information more readily available to patients. React quickly to problems and ensure everyone involved in the process is fully aware. Do not keep implanting devices when problems are being noticed, put a hold on use just while it is adequately investigated. Ensure reported problems are monitored by an independent central body so problems can be spotted quickly, and the manufacturers are not involved in this process to ensure no biased interest”.
Missed opportunities

“I worry about how the metals ions have reacted with my body and the effects we may not yet see. My first hip replacement I saw as something I needed to nurture and protect as this had a lot of years to help me with and that has been robbed. What will I do in years to come, has this stolen my best shot?”
Contacts

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