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1 Title Page

2

3 Meet the Researchers: an alternative method of engaging patients with research in

4 mesothelioma

5

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26 **Plain English Summary**

27 There are new ways to engage people with science and research but many patient support groups
28 and charitable organisations still hold traditional meetings to provide updates on their activities and
29 to report new developments in their field of interest. These meetings often feature presentations
30 given by medical doctors or, in the case of research-focussed organisations, by research scientists.

31

32 Receiving feedback from people who are confused and sometimes upset by some types of
33 information, and the way it is presented, at meetings made us think about better ways for
34 researchers to discuss their ideas for new research, or share the findings from completed projects,
35 with patients and members of the public.

36

37 This article describes a method of public engagement called “Meet the Researchers” that enables
38 people to hear about current trends in research face to face with the researchers planning or
39 conducting it. “Meet the Researchers” is designed to promote discussion and allow questions to be
40 asked in a relaxed and informal way, in small groups, which is less daunting than asking questions in
41 front of a conference audience. The aim is to break down the barriers between researchers and
42 patients, and enable conversations that will lead to meaningful engagement and a better
43 understanding of research. Additionally we aim to improve understanding of how results are passed
44 on to doctors and nurses and translated into improvements in patient care.

45

46 The method was tested with patients and was rated very highly by them in the feedback they gave.

47

48

49 **Abstract**

50 **Background**

51 Innovative approaches to engaging people with science exist but are often framed around
52 interactive events or social media technologies. Notwithstanding the availability of novel
53 approaches, many patient support groups and charitable organisations continue to hold traditional
54 meetings and seminars to provide information and updates on their activities, and report on
55 developments in their field of interest. In the case of research-focussed organisations, these
56 meetings often take the form of presentations delivered by clinical experts or research scientists.

57

58 Observation of mesothelioma patients, their relatives, friends and carers attending scientific or
59 clinical-themed meetings has shown that they can be confused, and sometimes distressed, by
60 presentations. This can be due to didactic presentations that are not properly targeted to this
61 audience and a lack of a general overview or summary at the end of meetings that would provide
62 some simple take home messages. This experience motivated the development of a less formal
63 method of sharing complex information and ideas, in a simplified manner. "Meet the Researchers"
64 aims to make researchers accessible to patients in order to raise awareness and understanding of
65 research and to explain how research translates into, and informs practice. This approach
66 encourages the use of plain English, removes the tendency to rely on power point slides to convey
67 the message and moreover, provides an opportunity for researchers to hear patients' views.

68

69 **Method**

70 Small groups of participants met face to face with the researchers planning or conducting research
71 into their condition, and discussed the topics in a relaxed and informal way. The researchers spent a

72 minimum of 20-minutes with each group before moving on to the next. Info-graphics or printed
73 hand-outs in plain English were allowed but no formal presentations were made.

74

75 **Results**

76 Our method has been evaluated using feedback data from three annual events held from 2016 to
77 2018: 100% of participants indicated that they liked the format "very much"(76.0%) or "quite a
78 lot"(24.0%); 80.4% found the topics "very interesting" and 65.3% found it "very easy" to ask
79 questions. Free text comments revealed themes of 'hope' and 'altruism'. Researchers also reported
80 benefits from participation such as learning about patient' priorities and networking.

81

82 **Conclusion**

83 "Meet the Researchers" provides a unique opportunity for mesothelioma researchers and patients,
84 relatives and carers to interact on a more equal footing. It stimulates discussion, promotes
85 understanding and provides a more informal setting for non-professional participants to ask
86 questions. It is a format that could easily be adapted for use in other conditions.

87

88 **Keywords:** Patient and Public Engagement; Methods of engagement; Evaluation; Mesothelioma

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94 **Meet the Researchers: an alternative method of engaging patients with research in mesothelioma**

95 **Background**

96 Mesothelioma is an asbestos-related cancer, usually but not exclusively, caused by occupational
97 exposure. It is classified as a rare disease, and it is recognised that patients with rare diseases can be
98 important partners in research.[1] Mesothelioma has a long latency period and is usually diagnosed
99 when the patient becomes symptomatic; at this stage treatment options are limited, and prognosis
100 can be short, hence the psychological burden of the disease is high. These factors limit the
101 willingness and the capability of patients to become actively involved in research. Building a research
102 portfolio that reflects the needs and aspirations of mesothelioma patients can therefore be
103 challenging.

104

105 **Framing the context of engagement**

106 Defining “patient engagement” is not straightforward; the literature on the topic is extensive but
107 muddled because the terms “involvement” and “engagement” are used interchangeably. A
108 qualitative study and systematic review concluded that while common concepts existed, the lack of
109 clear terminology and definitions create ambiguity and confusion among stakeholders when
110 referring to patient engagement. (REF Gallivan 2012) For the purpose of this paper therefore we
111 have chosen to adopt the definition of patient engagement proposed by INVOLVE: *Patient*
112 *engagement is where information and knowledge about research is provided and disseminated. (Ref*
113 *Briefing notes for researchers [http://www.invo.org.uk/posttypresource/what-is-public-involvement-](http://www.invo.org.uk/posttypresource/what-is-public-involvement-in-research/)*
114 *in-research/)*

115

116 Innovative approaches to engaging people with science are often framed around technology or
117 social media; for example the #whywedoresearch campaign.[5] Many museums, art galleries and

118 other special-interest centres have interactive displays and activity centres where people can see
119 how things work and try experiments for themselves or practice their own creative skills.
120 Additionally, the Velindre Cancer Centre in Cardiff[6] and other NHS organisations organise
121 laboratory visits in conjunction with charities like Cancer Research UK[7] and Cancer Research
122 Wales[8]. Science and research roadshows are also popular and successful approaches:
123 Southampton University’s Roadshow,[9] the CHaOS Roadshow[10] and the National Institute of
124 Health Research “I am Research” event[11] are just three examples. Closer to the method we
125 describe in this paper (but not identical) is the National Cancer Research Institute’s “Meet the
126 Expert” session,[12] which is held at their annual conference. These are informal sessions during
127 which attendees have an opportunity to meet an eminent researcher in their field (typically a
128 plenary speaker presenting at the Conference) and ask questions.

129

130 Notwithstanding these novel approaches, many patient support groups and charitable organisations
131 continue to hold traditional meetings and seminars to provide information and updates on their
132 activities and report on developments in their field of interest. In the case of research-focussed
133 organisations, these meetings often take the form of presentations delivered by clinical experts or
134 research scientists. Improving methods of engagement with researchers is a first step towards
135 developing partnership in priority setting and coproduction of research. (See Models of
136 engagement: Initiation REF) but evidence for the best way of achieving it is scant.(DOMECCQ)

137

138 In this methodological paper we describe a successful approach to patient engagement with
139 research in mesothelioma that aims to break down the barriers between patients and researchers,
140 and improve communication of research proposals and findings. An evaluation of the method is also
141 reported based on the feedback received from patients, relatives and professionals attending the
142 last three such annual charity events.

143 **Method**

144 From these salutary experiences the seeds of the “Meet the Researchers” concept were sown, and a
145 fusion of speed-dating (where a group of singles meet for a fleeting date with each other, typically of
146 3 to 4 minutes duration) and the Dragon’s Den (a popular TV series in which budding entrepreneurs
147 present their ideas to a panel of investors) emerged. The idea was driven by the need to move away
148 from a traditional meeting format in which professionals ‘address’ the audience, and to create an
149 environment more conducive to disseminating information through discourse and questions. “Meet
150 the Researchers” was designed to offer participants the opportunity to hear about current trends in
151 research in small groups, face to face with the researchers planning or conducting it, and enable a
152 discussion to flow in a relaxed and informal way. The aim was to make researchers accessible to
153 patients in order to raise awareness and understanding of research and to explain how research
154 informs and translates into practice.

155 The “Meet the Researchers” format was first enacted in a mesothelioma patient group at the June
156 Hancock Mesothelioma Research Fund (JHMRF)[9] Action Mesothelioma Day Event in Leeds in 2011.
157 Action Mesothelioma Day is a national event that takes place annually on the first Friday of July.
158 Mesothelioma charities, as well as local asbestos and mesothelioma support groups, organise public
159 meetings in different locations. The JHMRF is a charity that relies solely on donations from the
160 public. It is run by volunteers and has no paid employees. The JHMRF Action Mesothelioma Day
161 “Meet the Researchers” event is the charity’s annual public facing event; it is free to attend. Lunch
162 and refreshments are provided but participants are not reimbursed for attending. Participants
163 include mesothelioma patients, their friends and relatives; bereaved relatives; representatives from
164 other local cancer support groups, healthcare and legal professionals. A breakdown of participants
165 for the three years from 2016 to 2018 is shown in Table 1:

166

167 Table 1: Participants’ profile 2016-2018

Participant Groups*	2016	2017	2018	Total
Patients	14	8	17	39
Relatives/carers/ bereaved relatives	18	14	16	48
Healthcare and other professionals	8	2	5	15
Total providing feedback	40	24	38	102
Percentage of total attendees	47.6%	35.8%	51.4%	45.3%

168

169 A large room with circulation space was used and laid out in cabaret format: circular tables of 8 to 10
170 (see Image 1). The tables were numbered (1 to n) and two spare seats were provided at each table.
171 Patient participants were asked not to change tables during the day. A short introduction was given
172 to brief participants about the research groups attending, and how the meeting would be
173 conducted.

174

175 INSERT IMAGE 1

176 The researchers were allowed a minimum of 20-minutes at each table (timing can be flexible
177 depending on the meeting schedule but it is important to allow time for breaks, ideally after each
178 round of no more than three table sessions, and for summing up at the end). Each research group (1
179 or 2 representatives) was asked to prepare a brief introduction for a non-professional audience that
180 could be delivered in a maximum of 5-minutes. This was the 'Dragon's Den' pitch, which outlined
181 research interests or a specific research project; the remainder of the table session (15-minutes) was
182 open for the 'speed-dating' questions from the table (see Image 2). Aids to understanding in the
183 form of infographics or printed handouts in plain English were permitted, and a tablet or lap-top
184 could be used to show one or two pictures, graphs or diagrams either as part of the opening pitch or
185 to illustrate points raised in the ensuing discussion.

186 INSERT IMAGE 2

187

188 The research groups moved sequentially from table to table. Group 1 started at Table 1 and
189 progressed round the remaining tables to finish at Table 8; Group 2 started at Table 2 and moved
190 round to finish at Table 1 and so on. Flexibility is required in forming research groups and tables
191 depending upon the number of attendees, and availability of researchers. The options for group
192 configuration are either by specific project groups or by research discipline. Table 2 shows the
193 research groups participating in Action Mesothelioma Day 2017 as an example of the areas covered.

194

195 Table 2: Research Groups 2017

Group 1	Organic chemistry	JHMRF PhD Fellowship: A structure-activity study of JBIR-23 to determine the components required for activity against mesothelioma cell lines.
Group 2	Patient Research Ambassador	Patient and Public Involvement in research
Group 3	Clinical research	JHMRF funded project: SYSTEMS 2 A trial of radiotherapy for pain control in mesothelioma.
Group 4	Surgical research	MARS2: A feasibility study comparing (Extended) Pleurectomy Decortication versus no Pleurectomy Decortication in patients with mesothelioma. Funded by Cancer Research UK and Papworth

		Hospital NHS Foundation Trust.
Group 5	Thoracic Oncology	Immunotherapy of MPM by blockade of suppressor intratumoural Treg: target identification
Group 6	Cell Biology	JHMRF PhD Fellowship: Understanding the pathogenesis of mesothelioma.
Group 7	Applied Research	RADIOMESO: Receiving a diagnosis of mesothelioma: improving the patient experience. Funded by Mesothelioma UK

196

197 Table moderation is the role of the facilitator assigned to each table; this is a key role (suitable for a
 198 Trustee or charity associate with the right skill set). The facilitator assists with time keeping and
 199 eliciting or moderating the questions. They also keep notes for the summing up at the end of the
 200 event, although another person can be nominated by the table members to deliver the feedback.

201

202 Three to five minutes before each table session ended, an amber warning card was shown to allow
 203 groups to wind down the discussion. At 20-minutes an audible warning and red card signalled time
 204 to move on to the next table. It is very important to keep to time; if a discussion was unfinished or
 205 questions unanswered the table facilitator noted them so that unresolved issues could be dealt with
 206 in the breaks or during the summing up session. The research groups are required to move on to the
 207 next table to avoid disrupting the flow and delaying the schedule. It is also important to encourage
 208 attendees to remain with the same table group throughout the meeting to ensure they have the
 209 opportunity to meet all the research groups.

210

211 **Evaluation**

212 The JHMRF has used the “Meet the Researchers” format successfully for annual Action
213 Mesothelioma Day events from 2011 to the present. Feedback has been evaluated using two types
214 of data: quantitative descriptive statistics derived from a standard questionnaire, and qualitative
215 comments derived from the free text sections of the questionnaire and from email messages, texts
216 and thank you letters sent by participants after the event.

217 The “Meet the Researchers” format has proved to be extremely popular with people attending
218 Action Mesothelioma Day events compared to previous events (held from 2008 to 2011), that used a
219 traditional format featuring invited speakers and formal presentations. We acknowledge that
220 feedback data is generally skewed to the positive but feedback for “Meet the Researcher” events
221 has been much improved both in terms of numbers of forms completed and number and content of
222 comments. Combining data from 2011 to 2018, the proportion of feedback forms completed by
223 attendees (n = 379) was 42.0%, of which about a third were patients and more than half were
224 relatives and carers. Less than 10.0% of participants provided feedback in the years preceding 2011.

225

226 We aggregated our feedback data for the years 2016 and 2018. Rated on a four-point categorical
227 scale: “not at all”; “a little”; “quite a lot” and “very much”, 76.0% of respondents liked the format
228 “very much” and 24.0% liked it “quite a lot”. On a similar scale, 80.4% of respondents rated the
229 topics covered as “very interesting”. The question relating to presentation of information proved
230 more discriminating and indicates that, although the majority of respondents found the information
231 presented “very clear and easy to understand” (65.3%) or “quite easy” (25.3%), some still struggled:
232 8.4% of respondents rated the information they received as “moderately easy to understand” and
233 one respondent found it “not at all easy to understand”. This finding supports the evidence on
234 which the “Meet the Researchers” model is predicated: that giving information about research to
235 patients and carers cannot be construed as a simple and straightforward undertaking. Nevertheless,

236 75.9% of respondents found it “*very easy*” to ask the questions they wanted to ask, and this is
237 reassuring as it suggests that the “Meet the Researchers” format does indeed facilitate interactive
238 discussion and enables participants to ask questions more easily.

239

240 Feedback from JHMRF Action Mesothelioma Day events held before 2011 focussed on practical
241 aspects of the meeting like the venue and catering. Consequently suitable data from the events we
242 held using a traditional format is not available to compare with our feedback from “Meet the
243 Researchers”.

244

245 **Qualitative data**

246 Space was provided on the feedback forms for respondents to enter any comments about the day.

247 While not everyone took the opportunity to express their views, a surprising number of comments
248 were received on the forms and many verbal comments were made to, and noted by, table

249 facilitators. Many thank you letters, text and email messages were also received after the meetings.

250 The comments from all years were collated and three broad categories emerged:

251 1. Practical aspects of the meeting

252 2. The Future

253 3. Information

254

255 **1. Practical aspects of the meeting**

256 Problems experienced at the meetings, expression of thanks and appreciation, and suggestions for

257 future events were the themes associated with the practical aspects of the meeting. Problems

258 identified included noise from adjacent tables, difficulty hearing and fatigue. Noise, occurring as a

259 result of many conversations taking place simultaneously, was a common complaint across all years

260 despite an attempt to address the problem by changing the venue for a larger room. Increasing the
261 distance between the tables, albeit at the expense of some exhibition space, proved to be effective.
262 We did consider using breakout rooms but the short sessions are not conducive to moving between
263 rooms; moreover the cost to the charity would be prohibitive, as we would need a room for each
264 “table” of participants in addition to a large room for the collective sessions.

265 Suggestions from participants for future events were mostly practical hints and included allowing 5-
266 minutes at the end of each table session to confer among themselves about points requiring further
267 clarification or to formulate additional questions for the summing up session.

268

269 **2. The future**

270 Within The Future category were themes of hope and altruism linked with sentiments such as
271 ‘helping others’ and ‘leaving a legacy’. Examples of comments included:

272 *“Just being in front of a researcher gives me some hope – if not for me, for others in the future”* and
273 *“It’s great to know that not everything is doom and gloom – that there is hope - that research is*
274 *going on and that our input today may help researchers help mesothelioma patients even more.”*

275

276 **3. Information**

277 Information was a broad category within which many cross-cutting themes emerged. Many
278 respondents described the day as *“informative”* or said that they *“felt better informed”* but were not
279 explicit about how they had been informed; these comments were frequently linked to expressions
280 of thanks and appreciation. A few respondents were more specific about the information they had
281 received, for example

282 *“To be up close with the researchers was invaluable, to know what is going on behind the scenes is*
283 *reassuring. Lovely, informal, informative day.”*

284 *"I found the talk on radiotherapy for the new planned treatment for pain in meso patients very*
285 *informative, and the fact that it will be available at (hospital named) soon".*

286 At our most recent event we tried to tease out why attendees felt better informed by specifically
287 asking if attendees had found the meeting useful and to comment on this aspect. All respondents
288 (100% in 2018) indicated that they had found the meeting useful, and several comments were
289 received including:

290 *"It gave information on subjects we find difficult."*

291 *"Gave a deeper understanding of research."*

292 *"Keeps me up to date with research and developments."*

293

294 **The professionals' perspective**

295 We asked our researchers for feedback on the method too; some completed standard feedback
296 forms while others preferred to send comments by email after the meeting. We found that "Meet
297 the Researchers" posed challenges for some researchers, especially for those who had no patient-
298 contact before or who had always used formal PowerPoint presentations in the past. This new
299 format of meeting gave them the opportunity to develop/practice their communication skills to a
300 largely non-professional audience and it was perceived as a positive experience. Nearly all cancer
301 research grant applications now request a plain English summary and the Action Mesothelioma Day
302 meeting is an ideal forum to present ideas or results to a general audience. Meeting the sufferers of
303 the disease can also be a humbling experience for those who are not clinical researchers. A young
304 laboratory scientist attending the event for the first time commented:

305 *"It was a very valuable experience for me. I've never had any form of patient contact before so there*
306 *was a lot I took away from the day, and I had lots of feedback to give our team..."*

307 Another young clinical researcher commented:

308 *“Today has be a salutary reminder of why we do research and who for....”*

309 Even more experienced researchers felt the event was worthwhile, a research group leader
310 commented after the first event in 2011:

311 *“It was a very interesting new format as neither of us has been at a “speed dating” before! ...It*
312 *worked extremely well, as people who otherwise would not have asked any questions were more*
313 *confident in a small group setting to actively participate.”*

314 Another commented that it was

315 *“A worthwhile and educational experience for all”.*

316 The informal nature of the meeting also facilitates interaction and informal talks between
317 participating scientists, working on wide-ranging aspects of mesothelioma.

318 A full evaluation report of the feedback from Action Mesothelioma Day 2016 and 2017, including
319 quantitative data tables and a full list of free text comments, is available on the JHMRF website.[13]

320

321 **Discussion**

322 **The challenge of mesothelioma**

323 First-hand experience of the difficulties faced by researchers in communicating complex research
324 ideas and results to patients with mesothelioma led us to reflect on approaches to dissemination to
325 this patient group. Two examples, in particular, come to mind: first, watching patients bury their
326 heads in their hands or become tearful when presenters show (not very optimistic) survival curves,
327 or describe symptoms like difficult pain and breathlessness; and second, witnessing audiences in the
328 afternoon sessions of full-day events stare, silently and glassy-eyed, at yet another presentation with
329 numerous slides showing complicated tables and images. The most compelling observation,
330 however, was an encounter with a patient who left one of these meetings abruptly, saying: “I’m

331 *sorry, I just have to escape – I can't take any more of this.....it's all doom and gloom."* This was a
332 timely and cogent incentive to think more creatively about how we give patients information,
333 especially those with terminal conditions.

334

335 **The challenge of patient engagement in mesothelioma**

336 Patient engagement in research is now an essential requirement for research grant applications to
337 core funders like the National Institute for Health Research (NIHR)[14] and the Medical Research
338 Council (MRC)[15]. INVOLVE was established in 1996,[16] funded by the NIHR, to support active
339 public involvement in NHS, public health and social care research; and UK Research and Innovation
340 (UKRI) published a recent concordat for patient engagement in 2018.[17] As a research-funder, the
341 JHMRF is also keen to build a research portfolio that incorporates the views, and reflects the needs,
342 of mesothelioma patients and those close to them. Nevertheless, involvement in research priority
343 setting places a burden of responsibility on predominantly lay people, with varying levels of
344 experience and preparedness for the role, at a difficult time; and it is unrealistic to expect ordinary
345 members of the public to become consultants in research design and collaborators in the process of
346 the research; or shapers of health care policy without helping them to acquire the knowledge and
347 skills they need to become actively and meaningfully involved. "Meet the Researchers" is designed
348 to build rapport between patients and researchers thereby creating opportunities for patients to
349 shape the JHMRF research agenda in a way that is less demanding for the patients. By using the
350 football analogy of red and yellow cards, and the whistle to signal time, we aimed to reduce the
351 formality of the meeting and relax participants by adding a little fun to the event. The short,
352 interactive sessions diminish meeting fatigue and allow researchers and patients, relatives and
353 carers to interact on a more equal footing.

354

355 “Meet the Researcher” (or Meet the Experts) events are held in other settings but typically these are
356 themed around a single expert or a panel of experts, speaking with an audience.[12, 18] The NCRI’s
357 Dragons’ Den Workshop[19] is the closest methodological comparator as it offers the opportunity
358 for researchers to discuss ideas with, or pitch research projects, to small panels of patients,
359 corresponding to our table sessions at our “Meet the Researchers” event. The major difference is
360 that the NCRI Dragons’ Den is focussed on partnership, problem-solving and co-production in
361 relation to research proposals. “Meet the Researchers” is not designed to appraise research but
362 aims to raise patients’ awareness of research in mesothelioma and help them to understand the way
363 research is funded, conducted, reported and eventually translated into practice. An unanticipated
364 outcome from our qualitative evaluation of the method was the extent to which researchers
365 reported learning from the event. This supports the argument postulated by Staley (2017) that we
366 should rethink our definition of impact when evaluating patient engagement and involvement
367 activities.(STALEY 2).

368

369 The “Meet the Researchers” method of engagement is not limited exclusively to research. For
370 example, if the meeting focus is on care, “Meet the Experts” could be conducted in a similar way
371 with medical specialists, specialist nurses, allied healthcare professionals from different disciplines or
372 medico-legal experts forming the expert groups. In this example, however, it is important for the
373 table facilitator to moderate the table conversations effectively, and prevent individual cases
374 becoming predominant. This was a problem we encountered when we mixed research and clinical
375 experts for our “Meet the Experts” event in 2015.

376

377 Although we have not used our method for more targeted patient involvement activities, we
378 speculate that it could also be applied to identify patients’ priorities for research, or elicit patients’
379 views on study design when planning a new project. A 2014 review by Brett *et al* reported that lack

380 of preparation and training led some service users to feel unable to contribute to the research, while
381 other service users and communities reported feeling overburdened with the work involved.
382 Researchers reported difficulties in incorporating PPI in meaningful ways due to lack of money and
383 time.[21] “Meet the Researchers could potentially overcome some of these difficulties by linking
384 researchers with a large number of patients, without the time or expense of separate meetings or by
385 replacing reviews of lengthy, written research proposals with group discussions, thereby reducing
386 the workload for patients.

387

388 **Limitations of the method and evaluation**

389 There are some aspects of our methods that require refinement; for example providing additional
390 breaks during the sessions to reduce fatigue (both patients and experts) and managing the noise
391 level, which we overcame in 2018 by increasing the distance between the tables albeit at the
392 expense of exhibition space for our charity and our partners in the event. Feedback from all
393 participants also suggested that better briefing of researchers and table facilitators is required to
394 ensure that information is presented, and questions are answered, in a clear and accessible way.
395 Moreover, a brief outline of researchers and their field of expertise would be valued by both
396 professional and non-professional participants to enable table facilitators and attendees to prepare
397 questions, and researchers to cross-reference each other’s work to link up discussions more
398 effectively and not appear as isolated, unconnected examples coming from individual laboratories.
399 This latter suggestion was implemented at our most recent (2018) event and was well received;
400 evidenced by the fact that not a single programme was left behind at the end of the meeting.

401

402 We acknowledge that our evaluation is constrained by the nature of the data collected from
403 feedback forms. We also recognise that assessing the impact and benefit of engagement activities
404 for patients is difficult because methods of evaluation are under-developed and evidence is

405 limited.(STALEY 1) Reports of similar events are generally found only in organisations' newsletters
406 and on their websites. A scoping review revealed only one published paper reporting an evaluation
407 of event feedback.[20] This event (a national PPI day for thyroid eye disease) used a combination of
408 approaches to engagement, including didactic lectures, and focus group discussions. It received
409 excellent feedback: 52% of attendees at the event provided feedback and of these respondents, 88%
410 rated it very good or excellent. This is comparable with the feedback we received at our "Meet the
411 Researchers" event but it is not possible to comment on whether the combination of lectures and
412 focus groups is better than our informal discussion-based approach due to the limitations of
413 feedback data. Options for wider comparison of our results are limited because reviews of patient
414 engagement activities tend to focus on the impact, not the method, of engagement on research or
415 practice.

416

417 **Conclusion**

418 "Meet the Researchers" is a method of public engagement that provides a unique opportunity for
419 mesothelioma researchers and patients, relatives and carers to hear about current trends in
420 research face to face with the researchers planning or conducting it. The informal approach breaks
421 down the barriers between researchers and patients and enables interaction on a more equal
422 footing, without the use of PowerPoint presentations. This reduces the impression that researchers
423 are "talking to" the participants and helps stimulate conversations that lead to meaningful
424 engagement, and a better understanding of research.(PPT REF)

425

426 Feedback from our Action Mesothelioma Days has shown that participants felt empowered to ask
427 questions because they found it less daunting to speak in small groups than they would in front of a
428 conference audience. They also reported feeling better informed after the event and, importantly,
429 said they felt that their experiences and opinions were valued. This is an encouraging outcome

430 because being better informed and feeling able to contribute are springboards to future
431 involvement. Moreover, the participating researchers said they had benefitted and this too has
432 important implications for facilitating future research collaborations and co-production.

433

434 The practical details included in the paper will be useful to the organisers of patient engagement
435 events, particularly those seeking a new approach. The evaluation of the feedback provides some
436 insight into the application of the method and how is received by participants. The "Meet the
437 Researchers" method could easily be replicated or adapted for use in other conditions and settings.
438 It is also flexible and can focus on one theme or cover a range of topics from basic science to clinical
439 trials and health services research. In this way, patients can be supported to recognise the different
440 types and stages of research, and understand how results are passed on to doctors and nurses and
441 translated into improvements in patient care.

442

443 **List of abbreviations**

444	AMRC	The Association of Medical Research Charities
445	ELF	The European Lung Foundation
446	JHMRF	The June Hancock Mesothelioma Research Fund
447	MRC	Medical Research Council
448	NCRI	National Cancer Research Institute
449	NIHR	National Institute for Health Research
450	NHS	National Health Service
451	PPI	Patient and Public Involvement

452 UKRI UK Research and Innovation

453

454 **Declarations**

455 Ethics approval and consent to participate

456 Not applicable

457

458 Consent for publication

459 Not applicable

460

461 Availability of data and material

462 The data that support the findings of this study are available from the author upon reasonable

463 request, and with permission of The June Hancock Mesothelioma Research Fund.

464

465 Competing interests

466 The author declares no competing interests.

467

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471

472 Authors' contributions

473 KH developed the “Meet the Researchers format, planned and organised the Action Mesothelioma
474 Day Events, collated and analysed the feedback data and produced the manuscript. MP and ZT
475 critically reviewed the content and contributed to the writing of the manuscript.

476

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484

485 Authors' information

486 KH is a Senior Research Fellow in Applied Health at the University of Leeds, and a passionate
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489 Mesothelioma Research Network and the European Lung Foundation’s (ELF) Patient Advisory
490 Committee (PAC), and was elected to the ELF Council in September 2017.

491

492 MP is a Consultant in Sexual Health and HIV at the Mortimer Market Centre in London. She was
493 diagnosed with pleural mesothelioma in January 2017 and since then has become involved with
494 raising awareness of mesothelioma via blogging for Mesothelioma UK and the British Lung

495 Foundation. She is documenting her personal journey here notdoingthingsbyhalf.wordpress.com

496 She attended and was impressed by the “Meet the Researchers” event in Leeds in 2017.

497

498 ZT is a Reader in Cancer Immunology at Cardiff University. Her group has been working on the

499 immunology of mesothelioma for more than 10 years. Her main interest is to explore how the

500 immune system can be directed and empowered to attack malignant mesothelioma cells. Her

501 mesothelioma research has been supported by grants from the June Hancock Mesothelioma

502 Research Fund and the British Lung Foundation. She is a member of the Mesothelioma Research

503 Network and the College of Experts of the British Lung Foundation. She has attended several Action

504 Mesothelioma Day events in Leeds.

505

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