

## 2015 NCRI Clinical Studies Groups Scientific (CSG) Mentorship Survey

### 1.0. BACKGROUND

The NCRI Clinical Studies Groups (CSGs) oversee and develop cancer studies across the UK, which are included in the National Institute for Health Research Clinical Research Network (NIHR CRN) portfolio. There are currently 20 NCRI CSGs and 3 Advisory Groups, in which each group brings together the expertise and enthusiasm of key clinicians, researchers, basic scientists and consumer members establishing them as an expert voice in the cancer research community and in the development of clinical trials.

Historic data suggested the overall scientific mentor practice was inconsistent across the CSG consumer groups, with only some consumers receiving the mentor support. The need to clarify the role, purpose, tenure, expectations, performance and impact was identified through an exit survey, taken by consumers stepping down, and the CSG 2014 survey reports (of Chairs, scientific mentors and consumers). The NIHR CRN: Cancer's Patient and Public Involvement Lead subsequently commissioned the Strategic PPI Advice, Delivery and Evaluation Panel (SPADE), which surveyed CSG consumers with regards to scientific mentorship. In December 2014, the Survey for Consumers about Scientific Mentoring, which comprised of 15 questions, received 28 responses. There was also an additional discussion session at the 2014 NCRI Cancer Conference on 2 November 2014, which informed SPADE members when designing the questionnaire on Survey Monkey. This discussion took place amongst the former Consumer Liaison Group, giving feedback on scientific mentoring.

The responses analysed were used to create a report (Turner and Rawlinson, Jan 2015) with 11 specific recommendations:

- There should be clear guidelines regarding the role and function of a Scientific Mentor.
- Consideration should be given to providing Terms of Reference for Mentors so that they know what is expected of them and are, therefore, encouraged to mentor effectively.
- Mentors should be allocated when consumers are first appointed rather than consumers having to ask for assistance.
- A one-to-one meeting between the mentor and mentee should be arranged before the first CSG to help establish the specific needs of the mentee and the preferred method of communication.
- Consideration should be given to arranging structured time between the mentor and the mentee before the first 3 CSG meetings, possibly facilitated by the Executive. It might be useful to record the outcomes of the discussions.
- An example of a successful mentoring partnership should be shared to encourage and highlight good practice. This information could be added to the existing toolkit.
- Thought should be given to the best way of capturing and understanding the impact of having a mentor.
- Chairs of the CSGs should see mentoring as something they are responsible for and promote mentoring as a development opportunity for mentors.
- Any future coordinating resource should help facilitate the most appropriate support and development mechanisms for individuals, based on their learning needs, when assigned to a CSG.
- There should be regular reviews with consumers to identify and communicate any new requirements. This may include peer support between CSG and/or CLG members if required.
- It may be useful for a future coordinating function/Executive to collaborate on training or development requirements for Mentors and Consumers at the same time.
- Develop and distribute a similar survey for the Chairs and the Scientific Mentors

The results were then triangulated with the results gathered from the survey aimed at the CSG Chairs and scientific mentors.

## 2.0. 2015 NCRI SCIENTIFIC MENTORSHIP SURVEY

NCRI is developing its mentorship scheme and aims to produce guidelines and implement a formal procedure, with regards to the relationship between consumers, Chairs and scientific mentors, in enhancing consumer involvement within NCRI. As well as scientific mentorship, the NCRI also offers newly appointed consumers a 'buddy' who makes him or herself available for additional informal support, particularly during their initial meetings. A buddy is another CSG consumer, most often on the same CSG (unless there is a specific interest to join up members of different CSGs). The buddy and the NCRI Consumer Forum do not replace the support provided by the CSG scientific mentor, but rather supplement it.

The consumer mentorship survey was completed and produced by SPADE, in February 2015. The CSG Chairs and scientific mentors were then asked to complete a mentorship survey mirroring the consumers' mentorship survey, with additional questions considering the patient experience and training of mentors. These two latter surveys were initiated and coordinated by the NCRI Executive.

## 3.0. RESULTS

### 3.1 Participation

The NIHR 2014 survey, aimed at the consumers, had a 70% response rate, with 28 of the 40 consumers replying. 13 of the 20 Chairs (65%) and 16 of the 25 scientific mentors (64%) responded to the relevant surveys.

At the time of the scientific mentor and Chair survey, 38 out of 40 consumer seats on the CSGs were filled. The reasons for the low number of scientific mentors who received the survey are as follows:

- Two consumers on a specific CSG had the same scientific mentor
- Scientific mentorship arrangements were taking place for four consumers
- Five Chairs were also scientific mentors
- One consumer did not want a mentor

Five of the Chairs who responded were also scientific mentors, and only one of these Chairs responded to the survey in both capacities. Not all survey questions were completed fully and all responses were anonymous.

### 3.2 CSG Involvement

CSG membership is a 3-year term, with the option to continue for a further 3 years. Consumer membership to a CSG is a 3-year term year, with the option to continue for a further 2 years if appropriate. Most of the scientific mentors in the survey (50%) had been in their role for 4 years or more. Most of the consumers who responded to the survey (43%) had been in the role for 3 years or more.

### 3.3 Current Allocation of Scientific Mentor

32% of consumers, who responded to the survey, declared that they did not have a mentor, of which 27% stated they were not assigned one and the remainder gave "other reasons". See appendix 1 for "other" comments.

### 3.4. Consumer - mentor arrangement

36% of the scientific mentors, who responded to the survey, believed a consumer was allocated a scientific mentor after the first CSG meeting, but before the second, compared to 11% of consumers and 17% of Chairs. 3.6% of consumers stated the scientific mentor was allocated "well before the first meeting", in comparison to 8% of Chairs and 14% of scientific mentors. 40% of consumers considered the scientific mentor was allocated "shortly before or at the first meeting", compared to 25% of Chairs and 21% of scientific mentors (see appendix 2).

### **3.5 Communication between mentors and consumers**

50% of the Chairs, who responded, 86% of scientific mentors and 40% of consumers stated mentors and consumers communicated when consumers 'required' it. Provision of support to consumers was identified as via e-mail communication by 63% of consumers and 92% of Chairs, whereas most scientific mentors (92%) considered support to be in person at CSG or subgroup meetings. 75% of Chairs and 56% of consumers also considered support between mentors and consumers to occur in person at CSG or subgroup meetings (see appendix 3).

### **3.6. Role of scientific mentor**

The most identified areas for support by a scientific mentor were "provides advice for CSG meetings" and "explains scientific/technical issues and/or language terminology" by the Chairs (92% and 100% respectively), scientific mentors (62% and 62%) and consumer (53% and 47%). Other areas recognised as support include "provides advice with trial design and trial statistics" (75% of Chairs), "signpost to relevant information/papers/journals" (58% of Chairs and 46% of scientific mentors) and "provides support and guidance on consumer contribution to the CSG" (67% Chairs, 31% scientific mentors and 32% of consumers). Consumers (58%) mostly identified "other" areas for support of a scientific mentor.

### **3.7. Usefulness of contact with scientific mentors**

The Chairs considered the scientific mentorship for consumers to be 'very useful' and 'useful' (58% and 42% consecutively), whereas 17% of scientific mentors recognised their role to be 'very useful', and 66% considered their role as 'useful' and 'of some use'. A quarter of consumers, on the other hand, stated the scientific mentorship was "very useful", a further 14% considering it 'useful', and 10% stating it was 'of little use', along with 8% of scientific mentors.

### **3.8. Impact of scientific mentor on consumer**

67% of scientific mentors, 68% of consumers and 25% of Chairs considered the effectiveness of their mentor as not 'currently' being assessed. In contrast, most Chairs (33%) stated that the effectiveness of the mentor was assessed 'informally' but 'mutually agreed'.

### **3.9. Aspects of support given to consumers**

Areas of support required for consumers in the CSG varied between the Chairs, scientific mentors and consumers. See appendix 4 for the aspects of support considered.

The consumers suggested the following measures for improvement in support:

- Mentorship arranged at outset
- Awareness of development needs to address with mentor
- Formal arrangement with clear guidelines, outlining roles and expectations of mentorship
- Methods of contact, with suggestions for regional mentorship arrangements.
- Initial meetings arranged with the Executive's facilitation
- Structured time, provision of questions for enquiry
- Consent for mentor by consumer

A majority of the consumers found the induction training, scientific training, attendance at NCRI conferences and attendance at other conferences/seminars as a 'very useful' support mechanism (61%, 63%, 50% and 61% respectively). Consumers considered the non-scientific training and online learning for the consumers the least useful, with 33% and 30% of the consumers that responded not having made use of such support mechanisms. 7.1% of consumers did not have induction training and 15% had not received scientific training. Around 30% of the consumers had not had non-scientific training and online learning support.

The Chairs and scientific mentors considered various support mechanisms for an effective consumer in the CSG. See appendix 5 for recommended support mechanisms for the consumers. The current training of consumers received positive feedback, and consumers were considered effective within their CSGs. The Chairs' and scientific mentors' similarly considered the need for sufficient clinical trial training to be given to consumers.

### Buddy/Peer Support

64% of Chairs reported their consumers have a buddy mentor on the CSG, 27% were not aware whether they did or did not have a buddy mentor, and 9% said their consumer did not have a buddy. In contrast, 43% of scientific mentors stated that they were not aware if their consumer had a buddy mentor on the CSG.

Chairs considered the buddy support arrangement between consumers as very useful (28.6%), useful (42.9%) and 'of some use' (28.6%). Chairs, which were in regular contact with the buddy consumer and consumer in receipt of support, were more likely to be aware of the frequency of communication between the buddy and consumer. Of the scientific mentors that responded, 33% considered the buddy arrangement to be equally 'very useful', 'useful' and 'too early to say'. Some Chairs and scientific mentors did not consider it important to be aware of the level of interaction between the buddy and consumer on their CSGs, as long as both consumers contribute effectively to the group.

The majority of consumers (68%) did not have a peer mentor or buddy. Many consumers indicated their peer support arose as an 'informal' arrangement. Such arrangements were often dependent on the experience/willingness of existing consumers on the CSG. Some of the consumers that were involved in the support arrangement, 7.1% found it very useful, 17.9% found it 'useful' and 7.1% considered it 'too early to say'. See appendix 6 for consumer comments on the buddy/peer support arrangement.

## **4.0 QUESTIONS ONLY LIMITED TO TWO/THREE OF THE SURVEYS**

### **4.1. Survey for consumers about scientific mentoring 2014**

Of all the consumer responses (100% response rate), 42.9% of the consumers did not feel the need to provide further comments, and one suggested a redesign of the survey. Consumers suggested the following improvements for the mentorship scheme:

- Mentorship/support arrangement from outset
- Formalising the support arrangement, with expectations and terms of reference outlined
- Establishing good practice structured time for new consumer representatives with their mentor
- Allow for scheduling and geographical allowances
- Support from others at conferences, training and dinners
- Chairs responsible for mentoring, actively review, and promote mentoring as a development opportunity for mentors
- Mentors contact with consumer mentee prior to each CSG meeting and sit next to each other during the meeting

### **4.2. Additional questions in the 2015 NCRI Scientific Mentorship survey**

Chairs allocated a scientific mentor to a consumer on the bases of location, interest area and members actively volunteering to become mentors. Similar reasoning is given by scientific mentors, as to why they were chosen. In particular, one mentor stated that they had 'experience of consumer involvement and the chair of the CSG was aware of this' as the reasoning behind their allocation.

Most Chairs' and scientific mentor's have some degree of experience in the area of consumer involvement.

All of the Chairs that responded indicated they had not identified or been approached by the scientific mentors about training needs regarding consumer involvement. 71.4% of the scientific mentors responded that they did not have any training needs in the area of consumer involvement. In particular, a lack of information on expectations from scientific mentors, the need for training in advising consumers and the need to evaluate the impact of involvement of consumers, was considered by scientific mentors.

73% of Chairs suggested there were no issues raised by consumers over how well the mentoring scheme had taken place this year. Chairs raised the following:

- Need to formalise the mentorship scheme
- Need to identify and specify the role of the consumer and mentor, and expectations
- Chairs should enquire, keep updated and receive feedback from both the scientific mentors and consumers.
- Difficulty in arranging telephone discussions, due to other commitments
- Considers not having done a 'good job', as the CSG has 'lacked' direction due to a lack of a Chair
- Ensuring it happens and that the partnership remains active between mentor and mentee (not just on first appointment).
- From a mentor perspective, it is time consuming but rewarding.
- Ideal for more members of the CSG to share the workload
- Showcasing the experience and knowledge of the consumers joining the CSGs and what they can offer researchers. NCRI to signpost and makes the CSG members aware of the resources available.

## 5.0. CONCLUSIONS

The NCRI has a pool of experienced and committed consumers with a proven ability to deliver effective contributions to clinical research activities. It has become evident that consumer contribution is embedded in the work of most CSGs, as a key component of the integrated approach to cancer research developed by NCRI and Partners. Consumers use skills and knowledge beyond their patient and carer experience to inform CSG work, so it is paramount to enable this through areas such as training and mentoring.

## 6.0. STEPS TO TAKE FOR BEST PRACTICE

In order to assist in identifying where progress has been made within the mentorship scheme, there needs to be set recommendations for areas such as impact, provision of support and methods of communication, which will be adopted and shared throughout the CSGs. A mentoring strategy will address the following:

- Inform CSG members of consumer involvement and the contribution expected within CSGs. This would improve the system of members volunteering or agreeing to become scientific mentors, as they would be fully informed.
- Allocation of scientific and peer mentors
- Structure of roles clarified for all parties involved – roles and responsibilities identified
- Pre-determined meetings set for scientific mentors and consumers
- Annual review by CSG Chairs, possibly through performance reports
- Peer mentorship processes clearly defined – roles and responsibilities identified
- NCRI Consumer administration team to be updated of all changes and activities
- Survey to be implemented as part of the mentoring scheme, possibly every 3 years. Once the processes are in place, we can monitor practice more effectively
- Appraisals of consumer involvement and mentors

## 7.0. REFERENCE LIST

Patient and Public Involvement in the NCRI Clinical Studies Groups: Report of Consumer Members' Perspectives of the Scientific Mentors' Role, Authors: Lesley Turner, SPADE Chair, Janette Rawlinson, SPADE member, January 2015

## APPENDICES

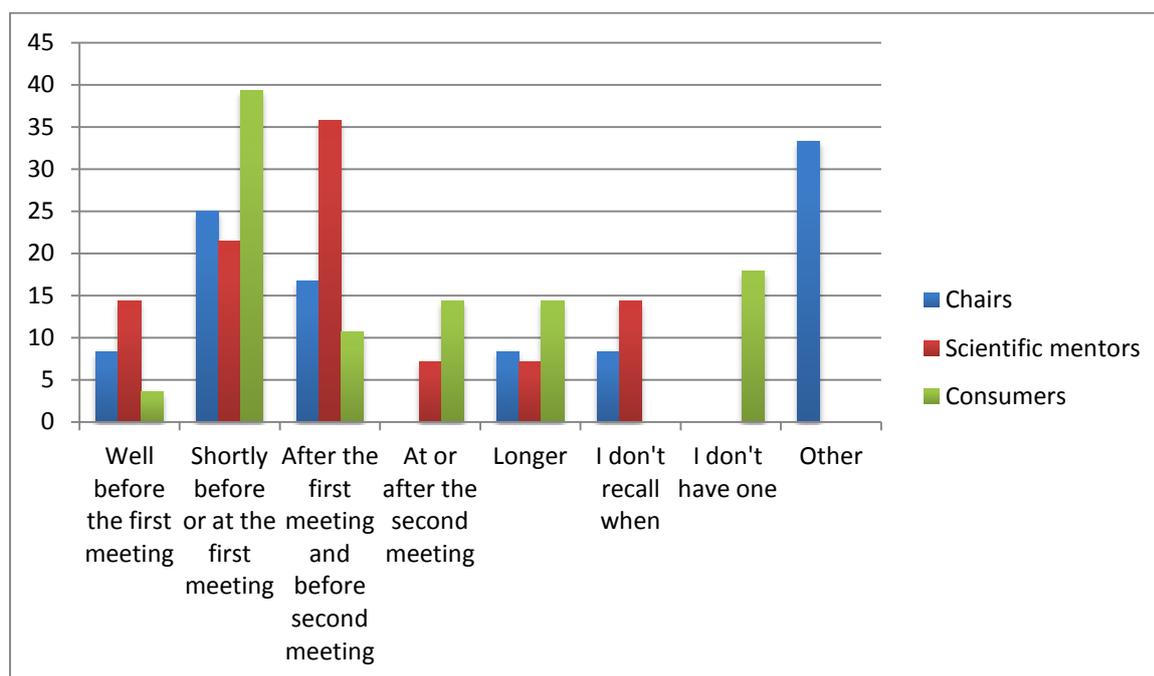
### Appendix 1

#### Responses under 'comments'

- I have only been allocated a mentor at my last CSG meeting
- I did not request a mentor, as I was a clinical scientist in an NHS clinical biochemistry department for 30 years before I retired and was reasonably familiar with the scientific knowledge required
- I was assigned a mentor but he left the group soon after I joined
- I was assigned a non-scientific, but knowledgeable mentor who has now left the CSG. Additionally I have a strong scientific background.
- I was assigned a mentor after several requests on my part but no contact was made and he left the group. I check science with my brother, a biology graduate, and I am a Physics graduate myself
- On a formal basis I have established a good relationship with the current Chair of the CSG [name ejected] and also with [name ejected], although I have to say that all the other CSG members have been extremely helpful when I have approached them. However I do think that having mentor assigned formally would reinforce the relationship.
- I had an effective mentor initially. My sub group involvement is now sufficient
- Subsequent to my interview and appointment earlier this year, the Biomarkers and Imaging CSG was more recently devolved into two discrete CSGs: Biomarkers and Imaging respectively. I have been delegated to the latter, which has not yet met.
- But can always ask CSG members on a need-to-know basis.

### Appendix 2

#### 3.4.1. Q5 (Ch), Q23 (M), Q7 (C). When was a scientific mentor allocated to the consumer?

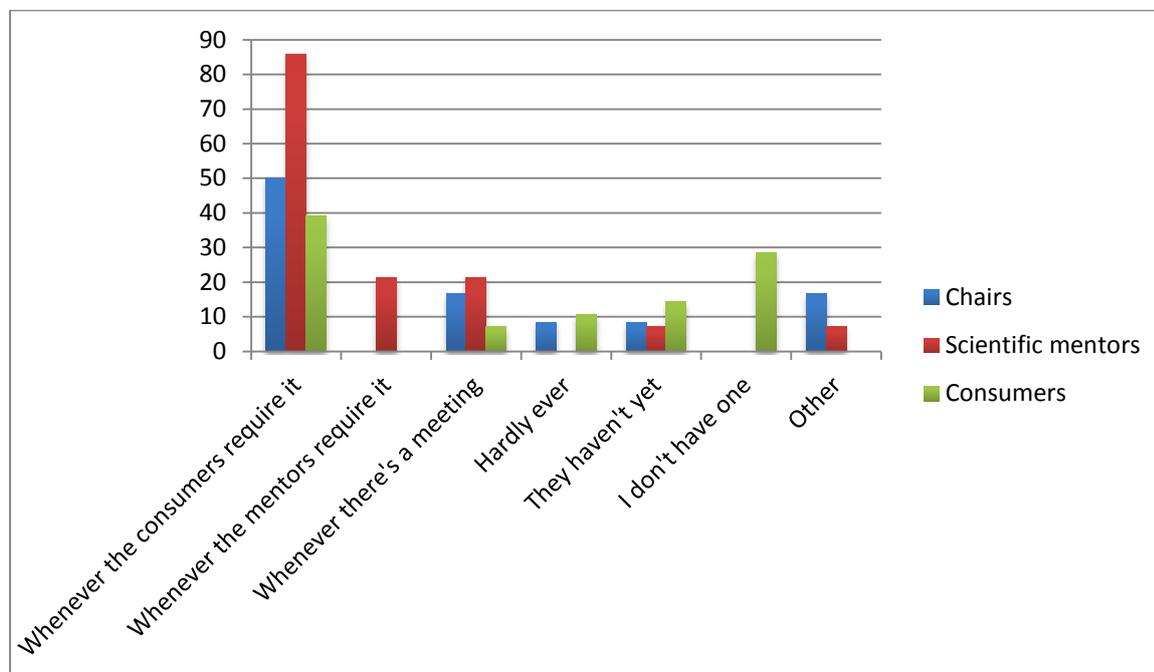


Answer choices	Chairs (%)	Scientific mentors (%)	Consumer (%)
Well before the first meeting	8.33	14.29	3.6
Shortly before or at the first meeting	25.0	21.43	39.3
After the first meeting and before second meeting	16.67	35.71	10.7
At or after the second meeting	0	7.14	14.3
Longer	8.33	7.14	14.3
I do not recall when	8.33	14.29	N/A

I do not have one	N/A	N/A	17.9
Other	33.33	N/A	N/A

### Appendix 3

3.5.1. Q6 (Ch), Q24 (M), Q9 (C). How often do you think the mentors communicate with the consumers?



Answer choices	Chairs (%)	Scientific mentors (%)	Consumers (%)
Whenever the consumers require it	50.0	85.71	39.3
Whenever the mentors require it	0.0	21.43	0.0
Whenever there's a meeting	16.67	21.43	7.1
Hardly ever	8.33	0.0	10.7
They haven't yet	8.33	7.14	14.3
I don't have one	N/A	N/A	28.6
Other	16.67	7.14	N/A

### Appendix 4

#### Aspects of support given to consumers

Chairs considered the support to consumers as being formal and informal, and including:

- Researcher and scientific background support
- Advice, including in areas outside CSG work
- Check point for what the role demands, what is expected of the member and protocols
- Support communication between members
- Peer support, including confirming value of the consumer and support during meetings

Scientific mentors considered support to consumers as dependent upon the consumer, in terms of interest and level of knowledge, and included:

- Ad hoc contact as required, including support and a friendly face at meetings
- Educational support and material sourcing in technical/scientific areas of knowledge
- Research and trial involvement of consumer and explaining of trials under discussion
- Supporting consumer networking
- Mutual support from having more than one PPI member
- Advice about charitable organizations

The consumers themselves considered the support they received (not of all whom had a scientific mentor) as including:

- Support and encouragement
- Support on 'complex' issues and point of call for questions
- Feeding back comments from consumer meetings
- Backup of research trials going on within the consumers' local area
- Guidance on how to influence and make a difference at meetings
- Colleague rather than help
- Guidance on science and explaining into lay language
- Provide greater understanding of some of the issues we're asked to comment on particularly where it is relating to a secondary cancer or another treatment beyond personal experience
- Reinforcement that "my perspectives useful"; showing how my views acted on

### **Appendix 5**

Chairs considered the following support mechanisms:

- Induction, training and education in: clinical trials, trial design, research and management of specific cancers; and, scientific terminology, principles and an abbreviation list
- Scientific mentorship
- Buddy support for informal support and guidance
- Sharing information with more experienced consumers

Scientific mentors considered the following support mechanisms:

- Defined role and expectations of consumers
- A structured training package, including induction
- Consumer appointment for 5 years, to enable confidence and experience in role
- Individual assessment to signpost effectiveness and communicate their effectiveness to all CSG members

### **Appendix 6**

Consumer responses to the buddy/peer support arrangement included:

- My mentor for the first three years ... on a different CSG. He was very helpful but the fact he was not on my CSG meant there were limits to what he could do.
- I guess [name ejected] took that role on informally and has always been great.
- I use the CGL and members ... to pose any questions and gain clarifications and understanding
- My co lay member has guided me through, and the rest of the committee have been helpful
- I meet the other person on my CSG before meetings and he has supported me and guided me at the meetings.
- No formal peer mentor. I have however learned a great deal from discussion with peers.
- The two CSG representatives in situ when I was appointed provided little support or role modelling. I've had a lot more support from [name ejected] and feel the two of us work well together.
- My peer has always been extremely welcoming, accessible and helpful. I know I can contact her with any question.
- I am well supported by the other consumer rep in the CCG who has been a great unofficial mentor/buddy!
- When I first started there were 3 Consumers on 'my' CSG. 1 was very supportive and helpful but was 'retired' soon after I joined. I have had very little input from the remaining Consumer.
- I talk with my other consumer member but this is probably more connected with other areas of volunteering i.e. patient support matters. I would have preferred a closer partnership and I think this is difficult sometimes if one consumer member has been on the group for a lot longer and is approached on a more regular basis to be part of projects, due to their knowledge of how the system works and their experience.

- No formal arrangements, but naturally and spontaneously occurring informal and reciprocal contact with fellow CLG and consumer members.
- I have tried to do this sort of mentoring officially in its official absence. I think it has been useful for those concerned and they seem to support this.
- In other contexts - very useful. Been both mentor and the person mentored and actually both roles are helpful.