Adding SUGAR: Service user and carer collaboration in mental health nursing research

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SUGAR

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Abstract

'SUGAR: Service users and carers group advising on research' is an exciting initiative established to develop collaborative working in mental health nursing research between mental health service users, carers, researchers and practitioners at City University London, UK. This paper will describe the background to SUGAR and how and why it was established; how the group operates; some of the achievements to date including researcher reflections; and case studies of how this collaboration influences our research. Written reflective narratives of service user and carer experiences of SUGAR were analysed using constant comparative methods by the members. Common themes are presented with illustrative quotes. The article highlights the benefits and possible limitations identified so far by members of SUGAR; outlines future plans and considers the findings in relation to literature on involvement and empowerment. This paper has been written by staff and members of SUGAR and is the first venture into collaborative writing of the group and reflects the shared ethos of collaborative working.

Key Words: Patient and carer involvement, mental health nursing, research

Introduction

Patient and public involvement (PPI) in health research is increasingly advocated due to its beneficial impact on the research and for those who participate. A recent review by Staley (2009) identified 89 published research studies that actively involved the public in health and social care research internationally. The review identified a number of impacts including: improving the research design and relevancy of research questions; helping researchers develop ethically acceptable research; improving recruitment and response rates; enhancing the collection and analysis of data; and enhancing dissemination of findings in an accessible way to the general public. Numerous challenges remain, including: ensuring that any involvement is meaningful and not simply tokenistic; researchers needing to give up/share power in the research process; researchers accepting that the research will often take a slower pace; and ensuring there are adequate resources, in terms of time, people and money, for additional training and support required for the patient and carer researchers (Staley, 2009). While many researchers found value in involving patients in the research process, many would welcome support in understanding the added value service user involvement could bring to their research.

There is a long history of patient (otherwise known as service user or consumer) involvement in mental health research and now numerous books and guidelines outline good practice in involving service users in research (Frankham 2009; Morrow et al. 2012), involving carers (family members and close friends) (Repper & Simpson 2011) and service user/survivor-led research (Sweeney et al. 2009; Wallcraft et al. 2009, Faulkner 2004). Kara (2013) provides a timely overview of mental health service user and carer involvement in research in England that includes case study evidence of added value.

Our own programme of research had a reasonable record of PPI with service users often on project steering groups and contributing advice and increasingly employed to undertake data collection. However, we were keen to move away from a reliance on one or two service users in order to obtain wider representation and a greater range of voices, including that of carers.

In this paper we begin with an overview of the establishment and activity of the Service User and Carer Group Advising on Research [SUGAR] and provide brief case studies of research collaboration with the group. We then offer an account from a researcher of what it is like working with service user researchers, a gap in the literature identified by Kara (2013). The remainder of the paper describes the methods and findings from a reflective evaluation of the processes and outcomes of SUGAR from the perspectives of the service user and carer members.

SUGAR: Service users and carers group advising on research

In 2009, SUGAR (Service User Group Advising on Research) was established at City University London. (The name was recently appended to explicitly acknowledge the involvement of carers). Funding was awarded through a National Institute of Health Research grant to establish and support the group for five years, as part of a programme of research led by Professor Len Bowers. This allowed the development, involvement and collaboration of mental health service users and carers in an on-going programme of mental health nursing research. Over the last four years, the group have received research training and collaborated with researchers on a large number of internal and external research projects.

SUGAR currently consists of 13 members: 11 service users and two carers recruited through the local mental health service provider using a 'job description' and person specification designed specifically for the role. The group reflects the rich diversity of London in terms of age, gender, sexuality and ethnic mix and includes people with a range of mental and physical illness and life experiences. It meets once a month and is facilitated and supported by the lead author and research colleagues to discuss and collaborate with SUGAR on all aspects of the research process, including: the identification of research questions, project design, ethical issues, recruitment, data collection, analysis, report and paper writing, dissemination and implementation of results. Members are provided with honorary university contracts that allows them access to the library, computer systems and other university services. They are remunerated for involvement in meetings and for any additional input.

In addition, members of SUGAR receive on-going support, education, training and development with individual and group teaching and self-directed learning. Training combined with genuine involvement and exchange with research issues and researchers has been linked with continued involvement in research (Lockey et al. 2004). Topics have included using IT, searching and reviewing literature, communication skills, research methods, ethics and governance issues, research roles and responsibilities, writing and presenting results. Members also attend University and other research events. Outside speakers including leading service user researchers and research network managers have been invited to speak to members to explain the wider context of public and patient involvement in research.

Active public and patient involvement and engagement in research

Over the last four years, members of the research team, research students and external collaborators have attended and discussed aspects of research programme projects with SUGAR on 46 occasions. On average, 11 SUGAR members and at least three members of the research team attend each meeting.   Usually, two research topics are discussed at each meeting and a range of methods are used to maximise service user and carer input, including large and small group work, written exercises, brainstorming, discussions and presentations.

Research projects have included reducing conflict and containment in acute settings; peer support in mental health and haemodialysis settings; protected engagement time; care planning and coordination; suicidal behaviour and self-harm; measuring health utilities; substance use and intoxication; using technologies; carers in crisis and acute care; seclusion, observation, and sensory rooms; medication information; acceptance and commitment therapy; self-stigma; staff attitudes; mental health of mental health professionals; HIV screening in mental health settings and supporting parents on acute wards. Topics discussed have included:

- Exploring a range of ideas for research studies
- Potential interventions to be used in studies
- Recruiting patients to studies

- Designing patient participation leaflets

- Writing the preface to a monograph

- Ethical issues

- Developing research questions for staff and patients

- Developing interview schedules for staff and patients

- Piloting interview schedules and questionnaires

- Initial findings and results, including systematic reviews of literature

- Dissemination of results

Examples of SUGAR collaboration in research

> **Peer Support Study: pilot trial of peer support for patients discharged from mental hospital***
>
> The idea for a 'buddy system' or peer support on discharge from hospital was suggested by the service user researcher on a previous study.
>
> Design of the study, ethics application, recruitment and selection of Peer Supporters, and framework analysis of qualitative data all involved members of SUGAR who also discussed progress updates and results.
>
> Three service users and a carer member of SUGAR were also members of the Project Advisory Group.
>
> *Led by Alan Simpson

> **Safewards Trial to test an intervention to reduce conflict and containment on mental health wards***
>
> Discussions with SUGAR about the design and content of the Safewards study have taken place throughout the study since its inception.
>
> Collaboration with SUGAR has led to changes in the content of the interventions incorporated into the Safewards trial; and which of the shortlist of interventions were chosen for use in the initial pilot study. They shaped the content of the final interventions in the cluster RCT and gave helpful advice on how these might be applied.
>
> Currently the SUGAR group are involved in discussions about maximising dissemination and implementation of the successful intervention.
>
> *Led by Len Bowers www.Safewards.net

Experience of working with SUGAR by Karen James: Research Worker, Conflict and Containment Research programme, Institute of Psychiatry, Kings College London.

What has been your experience of SUGAR?

I have been attending SUGAR for about three years now, and at every meeting I have learnt something new. I have really enjoyed getting to know the group – they are welcoming and friendly, but at the same time, very honest and forthright with their views. Overall, it has been a fun and informative experience.

What have you learned?

By listening to SUGAR I have learnt a lot about the experiences of people who have been admitted to a psychiatric ward. I have learnt to never assume you know what other people will think of something.

Often in academia we only present our work to other academics, and I've learnt how valuable it is to talk about your research to people outside academia - especially people who have direct experience of your research topic. The group always come up with new ideas, and a new way of thinking about things. They find different meaning in my research findings.

I've learnt how to talk about my research in (what I hope is) a clear and accessible way. I'm more aware of the technical language people often use when talking about research, and I've learnt that what I think are the most interesting research findings, aren't always the most relevant to other people, think carefully about what are the most interesting and relevant research findings.

SUGAR group members often have a lot to say, and debate can get quite heated at times so I've learnt a lot about how to facilitate a group discussion.

What has been challenging?

The group are very honest and forthright with their views, and I wouldn't have it any other way, but I have had to learn not to take criticism too personally! Sometimes I have spoken to the group about something that has not been that interesting to them, or perhaps something I haven't explained very well, and it has been difficult to keep their attention.

Do you think SUGAR has influence the research that has been presented to the group?

Yes, I think it has. SUGAR helped us design some of the interventions for the Safewards trial. They also helped me with my PhD, which is looking at how people who self harm are supported when they are admitted to a psychiatric ward. The group taught me a lot about the meaning of self harm, and helped me to understand why people do it. They also introduced me to the concept of harm minimisation (that people should not always be prevented from self harming on wards) and this is something I have chosen to explore further in my PhD work.

Additionally, SUGAR members have been recruited as members of study steering groups and lived experience advisory groups by core and external research staff and contributed to educational programmes at the University. Joint presentations and workshops have been given at a number of international and national mental health nursing research conferences and events. The SUGAR model has been cited as an example of good practice (Repper & Simpson 2011; Terry 2012) and has now been replicated within the School of Health Sciences through the establishment of the Kidney Research and Education Initiative (KREI) (Chamney et al. 2012).

Reflective Evaluation: Aims and design

In the remainder of this paper, we present the methods and findings of a reflective evaluation of the processes and outcomes of SUGAR from the perspectives of the service user and carer members. Reflective evaluation has been employed in studies with nursing students and staff to encourage active deliberation on particular processes or activities and usually involves focus groups or interviews (Platzer et al. 2000). In our study, we decided to employ a method of reflective writing as some members felt more able to express their views through such an approach. Reflective writing and use of journals has also been used successfully with students (Cherima 2007).

Methods:

SUGAR members wrote short reflective pieces about their experiences of being a SUGAR member for a poster presentation and workshop delivered to the International Network of Psychiatric Nursing Research (NPNR) conference in Oxford, England in 2012. Following the conference, members were asked to add to this writing or provide a more detailed reflection of their experiences to inform this paper. Five key headings were agreed to structure the writing:

1. What has been your experience of SUGAR?
2. What have you learned?
3. What has been challenging?
4. Why do you stay a member of SUGAR?
5. Do you think that SUGAR has influenced the research that has been presented to the group? If so, in what way? If not, how might this be improved?

Eleven members submitted pieces of writing. Not all followed the suggested headings. Over several meetings, printed copies of each other's writing were distributed amongst members of the group who conducted a line by line coding of all transcripts using the constant comparison method to identify themes. Twelve people took part in the analysis, aided by several members of the research team. Emergent themes were identified and circulated for further consideration and refinement and the resultant key themes with sub-themes are presented below.

Add: Table 1: Themes from constant comparative analysis of SUGAR member writing

Findings

Seven key themes with sub-themes were identified (Table 1) and are now explored in more detail, with illustrative quotes. Members chose to use their real names to identify quotes.

Personal growth

SUGAR members described their personal growth through involvement with the group and the research programme. This included learning; compassion and empathy; listening; understanding; tactfulness and diplomacy; communication skills; and increased confidence.

> *I have personally learnt the art for diplomacy when I come to meet different types for people in the same space. There are many different opinions and these opinions may come from places that are uncomfortable for me personally. However the exposure is something that has enabled me to grow in compassion and understanding. (June)*

> *I've also learnt to be more tactful, respectful, and considerate to the other members of the group and of their opinions. (Mandy)*

> *Liaising and communicating with different kinds of people with different personalities has made me to be less intrusive and talk with care. (Fadeke)*

Others described the new skills and knowledge they had gained, such as giving presentations and understanding and being involved in research.

> *I learn about different things, for example, how the stages of research are processed, how to ask research questions, how to collect data in research, and most of all*

funding and how that works in research. I also learn from other members in the group because we all have different experiences as service users and carers. (Claudette)

I have learned about research methodology, coding, extrapolating themes and presentations. This is refreshing and further expanding my previous learning in the fields of sociology and psychology. (Jay)

I feel that I have learnt skills such as talking in big groups. (June)

I have learned new skills, such as communication skills, presentation skills, and how to do research. (Nelly)

For many, being genuinely listened to and respected by the researchers was important.

What SUGAR has given me is the confidence to know my experiences are something and are listened to as well, and all the new knowledge I've learned from all the people who have spoken in all the different roles in the mental health field, and they also want to hear what I've got to say. My voice is being heard. (Mike)

I've gone from being quiet and not joining in, to being confident and joining in our discussions. (Mandy)

Your views and contribution to discussions is taken seriously and you get feedback, so this feedback gives you confidence to make another contribution. (Fadeke)

I feel that my opinions, views and experience as a carer are recognized and valued. This is vitally important as so often I have felt isolated, marginalized and "invisible" in society. (Jay)

When researchers seek our advice, admit their lack of expert knowledge, listen with respect to our suggestions, empathise with our experiences, it can validate us in a way nothing else does. (Richard)

Life experience (pre-SUGAR)

Several members wrote about their life experiences prior to joining SUGAR, providing some context to aid understanding about what had been gained through SUGAR.

> *I have three sons who have mental health support needs and I have found the opportunity to talk about issues that affect us as a family from a carer's point very empowering for the services and my family. I have been using services for many years and have seen the negative side of them. I feel that I can talk about this in the group and people care. (June)*

> *A major effect of having any degree of mental ill-health/distress is alienation. The stigma attached to mental illness leaves you (left me?) feeling isolated, despised and rejected, abandoned and useless. Things are done to you and for you over which you have no control, no say. Adding SUGAR to this sour mixture removes the rank taste. (Richard)*

Inclusion and Empowerment

Members described a sense of purpose and pride. Others talked of empowerment in relation to their involvement in research aimed at improving mental health services. A feeling of strength was drawn through collaborating with other members of the group.

> *It gives me a purpose in life. It gives me a sense of belonging, which is very important in a big city like London. It has brought me from the margin of the society to the mainstream. (Jagadish)*

> *I enjoy being a member of the group. It provides me with opportunities I otherwise would not have in my life. It gives me a vital focus outside of my caring role. It has increased my confidence and reduced the feelings of marginalization and isolation I was experiencing. (Jay)*

> *I like being a long-term member of the SUGAR group. It gives me a sense of importance that we are a part of a group who help in research and other projects.*

We are the only group of this kind and our group is a friendly and supportive group, which I feel comfortable with. (Mandy)

I have found the opportunity to talk about issues that affect us as a family from a carer's point very empowering for the services and my family. (June)

Service users and carers learned through sharing experiences within the group while discussing research topics. At times the learning came from an appreciation of a mutual or shared experience or perspective, at others times from a recognition of different experiences and viewpoints.

I feel that the group has a very good mix of people from different backgrounds, social economic states, educational, gender, nationality and sexuality this has been an asset for the work we are doing. (Isaac)

Collectively we as service users draw strength from each other. (Mary)

I also learn from other members in the group because we all have different experiences as service users and carers. (Claudette)

Sometimes when you use services you may experience something that you are unsure if that is something personal or if it a services problems: when you are able to have conversations with others who have had the same experiences as you have and they are the same. (June)

I think SUGAR has helped me in many ways. We all learn from one another, which makes it feel even more special to me. (Mandy)

Being able to share my own experiences in the period of isolation and anxiety, it gives value to my experience. (Mary)

Challenges

For a few members of SUGAR, the challenges lay in learning and understanding new knowledge about research and engaging with complex research ideas and discussions while managing serious mental health problems and at times periods of recurring ill health. For

others the challenges lay more in the dynamics of working with other people in a diverse group, many with strong or different views and opinions.

> *At first, being in a research group like (SUGAR) was very hard for me as a person with mental health issues. I had to learn to overcome my anxiety and fears. (Claudette)*

> *Attending the group meetings even when I was very anxious and depressed. (Mary)*

> *For me it's mentally draining most of time, but also interesting. (Claudette)*

> *The most challenging thing about the group is when there are disagreements between its members. (Nelly)*

> *As a carer suffering exhaustion it has been a challenge to attend the sessions both in terms of my caring commitment and my own health problems. (Jay)*

Frustrations around time keeping was mentioned by some members while others were annoyed when others criticised them for being late! The carers within the group wrote of the challenge in ensuring the carer's voice was heard and that their viewpoint was easily marginalised or ignored by some researchers.

> *I find it challenging when the SUGAR group is referred to as solely a service user group and no mention of the two carer members as this further compounds the feeling of being invisible/marginalized/un heard as it is already challenging enough in other groups. (Jay)*

Friendships and Support

Members wrote about their enjoyment, of friendships that had developed, of a sense of belonging and of being appreciated, valued and accepted. For many the acceptance and

support provided by fellow members and the facilitators was a key aspect of experience. One carer spoke of the sense of hope her involvement had given her.

Our group is a friendly and supportive group, which I feel comfortable with. I also feel inspired and appreciative of other members of the group. (Mandy)

Providing support and encouragement to each other. (Mary)

It helps that Prof. Alan Simpson and Prof. Len Bowers were mental health nurses in their field for many years, and Dr. Julia Jones has worked with and supported students with mental issues for years. They also know how service users' needs are met. (Claudette)

So, and then, with the help of Alan and Julia. They are very friendly. And I begin to listen. I persevere. I don't let other people attitudes bother me with the help of the mentors. The way they are very accommodating, warming, empathising. (Mary)

If you do not want to talk, you are not under any pressure to do so and you are not made to feel uncomfortable for not talking. (Fadeke)

Working with people that have mental health problems has given me hope for my sons. (June)

Opportunities

Most SUGAR members had taken part in delivering presentations and a workshop at various conferences and events and contributed to a poster. These opportunities to take part in mainstream research conferences were greatly appreciated and amplified feelings of being listened to, taken seriously and respected.

We went to conference we have our poster. We were able to stand up in the group. They ask questions from us, they learn from us. Everyone wants to come to the

SUGAR group. An opportunity for mindfulness, communication and learning from successes and mistakes. (Mary)

We get opportunity to attend conferences where I interact to people from all over the world. I also attend other events organised by City University. (Jagadish)

Becoming a SUGAR member has given me a renewed sense of confidence to purse academic learning and I have now obtained a place at college. (Jay)

Two former SUGAR members left after two years; one to take up a full-time employment, the other to pursue a number of other work commitments. Both felt the SUGAR experience had contributed to their development.

Outcomes/influence

Through taking part in SUGAR over an extended period of time, members were beginning to see some of the outcomes of their contributions and appreciate the influence they had on studies. Some members were more cautious in their appraisal and that it was perhaps too early to tell.

We have fed into the different types for research and made a difference there. (June)

Changes that have happened have been that researchers have started implementing the projects that SUGAR has helped to fine tune. (Fadeke)

Yes, I think SUGAR has influenced the research that has been presented to the group, because as SUGAR members we have different ideas, and also we are able to draw from our own life experience. (Nelly)

There are some workers that you can just tell that they really value your opinion. There are some professional that want our involvement time and time again. [But] I feel that some presenters just pay lip service to us as a group. There needs to be more decision-making from members. (Isaac)

> *Yes I think SUGAR has influenced the research presented. At several sessions the researcher has amended the wording of their work or said that they hadn't thought of a particular idea/theme after hearing comments from group members. Plus SUGAR has actively worked with researchers to create the work e.g. the scenarios recently presented at NPNR Conference. (Jay)*

People also recognised the development that had taken place and the further potential for SUGAR as the group developed as a strong network of people with a range of lived experiences. One member reflected on the challenges still faced.

> *A vision of a networking group of expertise working together. Collectively we as service users draw strength from each other. (Mary)*

> *I feel that we have a long way to go when it comes to service user involvement. However sometime as services users we are unable to have the power and a foot in the door is sometimes better the nothing. Sometimes I have felt that we as a group need more power and take more ownership. (Isaac)*

Discussion

Collaborating with mental health service users and carers through SUGAR has undoubtedly been advantageous for the academic research team and their research partners and students. Research proposals and activities have been refined and improved through discussion and consideration of the user and carer perspectives, as illustrated above. One test for the research team is to explicitly identify and describe the impact of that involvement in publications reporting results of studies as such impact is frequently not reported even where participation has taken place (Staley 2009).

This paper illustrates that there are also significant benefits for the SUGAR members. Through the writing exercise and analysis, members identify a range of personal gains, growth, opportunities and development that has come about through their extended involvement with SUGAR and academic research colleagues. The combination of a friendly, supportive group environment and the opportunity to engage with purposeful activities focused on generating high quality research ultimately designed to improve mental health

services is a winning formulae. As was pointed out by one member, participation with SUGAR meets all the five criteria that have been identified for maintaining wellbeing: connect, be active, take notice, keep learning, and give (New Economics Forum 2011).

The deliberate shift away from relying on one or two individual service users or carers for specific projects has undoubtedly been successful and reduces the risk of placing too much pressure on lone participants, widens representation and provides opportunities for group teaching and learning of research processes and methods. Additionally, there is a synthesis of learning that takes place as the various contributions and perspectives complement and feed discussions leading to new ideas and approaches.

One challenge still to be adequately addressed concerns the involvement of carers within the group. Kara (2013) highlights the predominant failure to treat carers as separate from service users or, often, to not include them at all. Most of the guidance on how to involve service users in research refers to carers, but usually as an afterthought or with little consideration of their distinctive perspectives or specific needs (Repper & Simpson 2011). For a long time, SUGAR contained just one carer. The recruitment of a second carer has strengthened the carer voice and the research team are beginning to make renewed efforts to consider how best to ensure engagement with carers is truly meaningful.

The success of the group brings other challenges though. SUGAR was commissioned through a five-year grant linked to a specific programme of research that is now coming to a close. The search for future funding is underway. However, this natural junction also provides an opportunity for a review and reconsideration of our methods and the best way forward. The group was established with the distinct purpose of support for a programme of academic research. It was not designed or funded to support user-led research and this was made clear from the very beginning. However, through participation in the group, the training and development provided, and the numerous discussions about research studies and methods, at least some members would be ready to take on a greater leadership role in the future development and running of the group and in determining the direction and focus of some research projects. But this needs to be explored with sensitivity. The analysis reported in this paper makes it clear that the success of the group is due in some part to the facilitation and support provided by members of the research team, who have drawn on

mental health nursing and related skills to provide a safe, supportive environment. Any changes in where the power lies may also provoke tensions between staff, service users and carers that rarely surfaces at present but which is frequently reported elsewhere (Kara 2013).

Different models of service user involvement in health and social care education and research have been articulated (Chambers & Hickey 2013), often suggesting a continuum from lower levels of consultation, through more meaningful collaboration and ultimately user-led or emancipatory approaches. Beresford (2002 cited in Frankham 2009, makes a distinction between 'consumerist' approaches to user involvement and 'democratic' or emancipatory approaches. Whilst user-led research is determinedly about the redistribution or even seizing of power, a more 'consumerist' approach as exemplified by SUGAR is more limited in this regard and "allows for external input while the initiating agencies maintain control" (Frankham 2009, p. 20). Nonetheless, as Beresford suggests, empowerment is still possible through consumerist approaches and the term empowerment was used by a number of SUGAR members in their writing. Additionally, SUGAR members have drawn on their experiences to obtain other work experiences, education and employment suggesting that the members' abilities and self-efficacy were enhanced despite agencies maintaining ultimate control over the research.

Kara (2013) remarked that reflective accounts by researchers on working with service user researchers are rare but incredibly valuable (Gillard et al. 2012) if the research community is to learn from the experiences of others. Consequently, we intend to do just that in a study of community care planning where we are employing service researchers alongside the academic team to undertake interviews with service users and carers about their experiences of care planning and coordination (http://blogs.city.ac.uk/cocapp/).

For most of us involved in the SUGAR experience over the last four years it has been a rewarding, friendly, thought-provoking and sometimes challenging place to be. Occasionally it has been frustrating and there has never been enough time to do everything we would like to in the way that we would like. Undoubtedly, friendships have been created and views have been changed. Importantly, the perspectives of service users and carers have

influenced and shaped a large number of research studies conducted by a group of mental health nurse researchers and their colleagues. There is much more to come. Sweet.

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Table 1: Themes from constant comparative analysis of SUGAR member writing

Higher order (main themes)	Lower order (sub-themes)
Personal growth	Learning
	Compassion/Empathy
	Listening
	Understanding
	Tactfulness/Diplomacy
	Communication
	Confidence
	New skills e.g. presentation, research
	New knowledge
	Being listened to and respected
Life experience (pre-SUGAR)	Family
	Education
Inclusion and Empowerment	Sense of purpose
	Collaboration/Shared experience
	Empowerment
	Power to change things
Challenges	Working within a group
	Difficult for carers' voice to be heard/marginalisation
	Disagreements/time Keeping
Opportunities	Conferences and events
	Education and work opportunities
Friendship and Support	Friendships
	Sense of belonging
	Being appreciated/valued/accepted
	Support/feel supported
	Hope
Outcomes/influence	To make a difference to research