



College of Psychiatrists
of Ireland

Wisdom • Learning • Compassion



INAUGURAL REPORT OF

REFOCUS

Recovery Experience
Forum of Carers and
Users of Services

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Foreword

It is a great privilege to present the inaugural report of REFOCUS, incorporating reports for three years from November 2011 to 2014. This report outlines how REFOCUS was formed and the work the committee has completed over the past three years.

We would like to take this opportunity to thank the members of REFOCUS, all of whom have worked so hard over the past three years, and who have contributed to making REFOCUS one of the most fulfilling and most productive committees of the College.

The commitment and dedication of REFOCUS members has been outstanding. They see their inclusion within the College of Psychiatrists as a great honour and opportunity and take their roles on the committee extremely seriously. As Co-chairs on the committee, we have learned so much. There has been an honesty, openness, understanding and compassion, which have been both humbling and instructive.

Up to now REFOCUS has used papers and presentations in order to enable their experiences inform the training and practice of psychiatrists. Members of REFOCUS have now joined some of the committees of the College and this is a further opportunity to increase communication with members. In the next year it is envisaged that more psychiatrists will join REFOCUS.

Along with the members of REFOCUS there are a number of other people who have contributed to its success. Andrea Ryder, as Manager of External Affairs and Policy, and Sibéal Farrell, Communications Assistant, set up the committee and most importantly provided ongoing administrative and emotional support to committee members. Also, Dr. Peter Byrne and members of the service user and carer forums of the Royal College of Psychiatrists provided invaluable guidance for our group.



Anne Jeffers
Co-chair



Kevin Jones
Co-chair

Introduction

The inaugural report encompasses the work of REFOCUS since its inception and first plenary meeting in December, 2011. In these circumstances, we felt that the best way to present the report was to have a structure incorporating the following elements: the history and membership of REFOCUS, the adoption of REFOCUS as the name for the group, the arrangements we agreed upon for the management of our meetings and relationships, the presentations made by various representatives of the College to our plenary groups, the papers we drafted and presented at various meetings of the College and our involvement with the various committees and faculties of the College.

History and membership of REFOCUS

REFOCUS, although not bearing that name at the time, was conceived by the College of Psychiatrists of Ireland as a forum where the views and experiences of service users and family members/carers would inform and influence all aspects of the College's business and, in particular, the training experience of young future psychiatrists. It was modelled on a similar forum established by the Royal College of Psychiatrists in the United Kingdom – SURF (Service User Recovery Forum) – which has been in operation in the United Kingdom since 2006.

In 2011 the Director, (Dr Anne Jeffers) and Manager, (Andrea Ryder) of the College External Affairs and Policy (EAP) Department initiated conversations with RCPsych in particular with Mr Thomas Kennedy, Communications Manager, Public Engagement RCPsych and Dr Peter Byrne, Consultant psychiatrist and SURF originator. Dr Byrne recommended a visit to a SURF meeting in London and meeting up with a previous member of SURF, an Irish man, Mr John Dixon, who had returned to Ireland. Both recommendations were taken up. The generous time given to Anne and Andrea by SURF members and John Dixon about SURF prevented possible pitfalls and time wasting and helped shape how a CPsychI forum could be formed and run. A format and budget was drawn up and approval given to set up a CPsychI forum. John, who became part of this new forum, was also involved in the formation process.

Various representative groups of service users and family members/carers were contacted to either nominate possible members or to advertise that the College was seeking members for this new forum. Following an application process, structured meetings were held between selected applicants and Anne, John and Andrea to tease out their interest and suitability as participants of this new forum. The first meeting took place in December 2011 with Dr Shari McDaid providing facilitation and guidance for all for terms of reference, modus operandi and so on. The full list of original and current members of REFOCUS is set out in Appendix 1.

“Support groups have many functions and benefits but having a safe, non-judgemental and confidential space to share one’s feelings and thoughts around what is sometimes a taboo subject is invaluable.”

“At my age, I am tired of fighting the system”

“We were unable to avail of any local services and in the early days of the illness particularly it would have been a really positive link to have had a community nurse calling and offering support.”



*REFOCUS at NCHD conference 2013
FROM L-R: Jeannine Webster,
John Kidney, REFOCUS Co-chair and
coordinator, Dr Anne Jeffers*

What's in a name?

For those not familiar with REFOCUS, the title for the group may seem puzzling. In fact, one of the tasks we undertook at our first few meetings was to choose a name which we felt might identify accurately what the group was about. After some debate and some interesting suggestions, the group adopted REFOCUS as its name. The name reflects the view that what concerned us was the need to inform the College and its various committees and training programmes, not only about the service user and family member/ carer experience of the mental health services in Ireland, but also suggestions for change and improvement. The idea of “refocusing” seemed to capture this objective perfectly. REFOCUS stands for Recovery Experience Forum of Carers and Users of the Services, reflecting the strong belief of the forum in the wellness and recovery philosophy.

Governance and Housekeeping

An understandable early task for REFOCUS was to establish terms of reference and a code of practice for the forum. To achieve this, an external facilitator was asked to monitor our discussions and to inform us about best practice in governance matters. At the end of this process, we agreed on operating guidelines. These are set out in Appendices 2 and 3. These guidelines are not set in stone, however, and have been reviewed by the group very recently.

A key decision taken by the forum at its initial meeting was that all members of the forum would participate on an equal basis and that there would be no sub group split along service user and family member/carer lines, as is the case with the analogous UK body. This decision is reviewed on an ongoing basis.

*“Recovery, for me,
is the discovery of
an acceptable and
accepting way of life
after or during mental
illness.”*

*CPsychI Spring Conference workshop.
Athlone 2013 FROM L-R Jeannine Webster
Anne Jeffers, Liam Hennessy
and Kara Madden*



Minutes are taken at every meeting and copies are sent to College Management. In December 2013, there was an external evaluation of REFOCUS. This evaluation made a number of recommendations which have since been introduced.

*“I found it really helpful when my
psychiatrist said, ‘you want to
stop medication, good; what are
you going to put in its place?’ I felt
I was being treated as an adult”*

Presentations made to REFOCUS

From its inception, the forum felt that it would be helpful if psychiatrists and trainee psychiatrists from the College were invited to present to the group to inform REFOCUS members about the nature of psychiatry in its various specialities in Ireland today. As a result, we have had a number of very informative talks and exchanges of views on areas as diverse as the training programme for young psychiatrists to the DETECT programme for early intervention in psychosis to the work of the forensic psychiatric services in the Central Mental Hospital. A full list of presentations made to us to date is set out in Appendix 5.



FROM L-R Kara Madden, Liam Hennessy and Jeannine Webster after presenting a workshop at CPsychI Spring Conference in Athlone, 2013

Papers written by REFOCUS

At its early meetings, REFOCUS decided that relevant papers with practical recommendations, which would be presented to the College, should be a central part of its work. This has proved to be an essential element of what REFOCUS is about, reflecting the lived experience of the members of the forum. All members believe that such papers, when presented to the College, will inform Irish psychiatrists and trainee psychiatrists how service users and carers/family members feel about the delivery of mental health services in Ireland. To date, REFOCUS has prepared papers on the experiences of carers of psychiatry in Ireland and the meaning of “recovery” for users of services. There are more relevant papers in the pipeline and these will be covered in our next annual report.

“I felt validated in my experience, when I met someone else who had been through something similar. It is so much easier to believe in yourself, if you can see someone else further down the road of recovery”



REFOCUS quarterly meeting in action



Medfest 2013, Co-chair Anne Jeffers and REFOCUS member Vivienne Dick

Presentations made by members of REFOCUS

REFOCUS members, both the service users and family members/carers, have also presented their journey of recovery through mental illness to delegates of the NCHD (non-consultant hospital doctors) conference and Summer School for medical students run by the College Trainee committees.

An obvious follow on to the preparation of papers by REFOCUS was the presentation of such papers to the College and its members. As a result, members of REFOCUS made presentations

in workshops and at various conferences. It appears that these presentations were well received although, being given to workshops, it meant that they “competed” with other presentations and did not reach as wide an audience as might have been wished. This is an issue the forum hopes to address in future. A full list of presentations is provided in Appendix 4.



REFOCUS stand at a EUFAMI conference May, 2013. Co-chairs Anne Jeffers and Kevin Jones

A REFOCUS meeting in action

Involvement of REFOCUS members with committees and faculties of the College

If there is one area of the work of REFOCUS where progress has not been as positive as might have been wished, it is the area of involvement with the various committees and faculties of the College. It is understood that, in the analogous committees in the United Kingdom, members of SURF do participate as full members of relevant committees. Up to now, the involvement of members of REFOCUS in committees of the

College has been confined to participation with observer status in the mock practical consultations with trainee psychiatrists and on the editorial board of the Irish Journal of Psychological Medicine.

Just prior to publication of this report, the trainee committee voted to include a REFOCUS service user and a family member/carer on each of their sub groups responsible for organising trainee events and activities. The newly formed External Affairs and Policy Committee (EAP) now includes a REFOCUS service user and family member/carer. REFOCUS welcomes these committee memberships as a positive step towards the practical value of REFOCUS in the College.

“The point is you never completely give up your own view. Part of you never relinquishes your alternative reality, if you can find a way to manipulate it into a recovery perspective that is what is important.”

“For me, recovery was about letting go of the anger”

Conclusion

In this inaugural report we have tried to give a flavour of our work over the last three years since we were established. Inevitably, some of the detail of our work and the contributions of key members of the College team who established REFOCUS and kept us going have been glossed over. Nevertheless, we would like to record our thanks to them for the role they have played. And it would be entirely remiss of us not to mention Anne Jeffers whom, without her commitment and conviction, it can safely be said, we would not be having this conversation.



Christine McCabe and a delegate at the REFOCUS stand. EUFAMI conference, May 2013

“We want psychiatrists to use more friendly open questions to get a discussion going – this should be a communication between two people, - don’t pry for proof of symptoms – don’t make a big deal of symptoms which could have the effect that someone won’t admit that they have been experiencing them.”



REFOCUS meeting September 2014. Ms Sibéal Farrell (centre with flowers) coordinator for REFOCUS on her last day with the College



CPsychI Summer School for Medical Students 2014. Mr George Bridges and Dr Anne Jeffers post George’s presentation on his recovery journey.

Appendices

Appendix 1.

Dr Anne Jeffers	Current (Co-chair)
Kevin Jones	Current (Co-chair)
Tony Blackmore	Current
George Bridges	Current
Liz Brosnan	Current 2014
Lisa Butterly	Resigned
John Casey	Resigned
Christine McCabe	Current
Ciaran Cobbe	Current 2014
Ciaran Crummey	Current
Vivienne Dick	Current
John Dixon	Current
Angela Dooley	Current
Colette Fahy	Resigned
Brian Hartnett	Current 2014
Julie Healy	Current
Liam Hennessy	Current (Co-chair for 2015)
John Kidney	Current
Kara Madden	Current
Eileen McCluskey	Current
Brian McNulty	Current
Derek Mullen	Resigned
Neil Powell	Resigned
Diarmuid Ring	Current
Jim Walsh	Resigned
Jeannine Webster	Current

CPsychI Office Team

Andrea Ryder	External Affairs and Policy Manager
Sibéal Farrell	Communications Officer 2011-2014
Micheál Clesham	Digital Communications Administrator
Niamh Mongey	Communications Officer 2014
Dr Clodagh Power	Trainee Committee Representative 2014

We wish to thank former members for their work and commitment to REFOCUS since 2011.

Appendix 2.

REFOCUS Terms of Reference

Aims:

To engage actively in genuine partnership with the College of Psychiatrists of Ireland so that training, ongoing competence and day to day practice of Psychiatry is informed and guided by those who have had experience of mental illness, or who have cared for those with illness.

Objectives:

- Improve mutual understanding and respect between College Psychiatrists/College members and those who use services.
- Contribute to the training of College members.

- Contribute to the development of good practice guidelines for College members.
- Learn more about Psychiatry.
- Signpost to a wider constituency of service users and family members.

Co-chair: Dr Anne Jeffers **Co-chair: Mr Kevin Jones**

The role of the co-chairs will be to plan the agenda and content of meetings as well as co-chair the meetings. Co-chairs are one psychiatrist (College member) and one nominated from and elected by the group.

Administration: College team members

Terms and Conditions for Committee members:

Membership will be for two years. Members will be expected to become involved in at least one project and/or activity of the committee in each year. Membership may be as an individual or as a nominee from an organisation. Members can leave at any time; this should be handled with sensitivity. New members will be considered after two years. Members can carry out a second term of two years.

Accountability:

The Co-chair of the Committee is the Director of the External Affairs & Policy Department. The Department reports to the College Management Committee and to College Council. Committee activity will be informed by the College Communication Strategy and the Codes of Practice for the Forum.

Meetings:

There are four to five meetings a year commencing 9.30am and finishing 4.00pm. Service users and carers will meet together; this will be reviewed midway through the first year and thereafter when required.

Meeting Documentation:

Members will be contacted one month in advance inviting agenda items. The agenda will be sent to committee members one week in advance. Minutes will be sent out to REFOCUS members within one month of the meeting to be reviewed at the following meeting. Any amendments to the minutes can be made at the start of the next meeting. Minutes will be sent to the College Management Committee and REFOCUS meetings /activity will be an agenda item of the EAP committee meetings. Some business may be conducted via email. Sub work group meetings will take place at the College premises or at a REFOCUS meeting or on the eve of or after a REFOCUS meeting.

Remuneration / Expenses:

Remuneration has been agreed by council as follows: At the end of the year, an honorarium will be given to members, for attendance at the Forum meetings. Members of the Forum who present at training days or conferences will be reimbursed any expenses incurred and will have conference fees waived for the day they present as with other procedures for presenters. Travel and accommodation expenses for meetings will be covered for those who require it for attending meetings.

Appendix 3.

Code of Conduct to Support Members of REFOCUS

An individual's health should always be considered as a priority, and participation in College activities should always be secondary to each individual's physical and/or mental health. Individuals who are unwell should not be penalised in any way because they are unable to attend meetings.

A member of staff will be identified to link with each service user or carer, before they attend the first meeting. This is to ensure the participant is aware of travel and accommodation arrangements which need to be made, and is also aware of the content of the meetings, how the meeting will work, and be the main contact should the person require any further information.

Through the Co-chairs it is important that everyone can speak at each meeting. It is important that committee members listen to each other, speak clearly, follow the direction of the Chair, and respect individual viewpoints.

It is up to Forum members to decide what is acceptable and what is not for the conduct of its own business. These rules can be decided at the first meetings and incorporated into this Code of Conduct. Individual Forum members must abide by these rules, and accept that, if their behaviour is not appropriate, they may be asked to leave the Forum.

All individuals on REFOCUS are representing their own individual views, even if they have been nominated by an organisation.

Contributions should be pertinent to the issue under discussion. Wherever possible, personal confidential information will be deleted from any circulated documentation.

Appendix 4.

Presentations and Involvement of REFOCUS members with committees and faculties of the College

College Conferences:

2014

NCHD Conference: Anne Jeffers, Jeannine Webster and John Kidney presented “Learning from the Patient”. They spoke with valuable insight on engagement with service users and their families, and on their own experiences of recovery respectively.

2013

Spring Conference: Sheraton Hotel, Athlone: Presentations given by Liam Hennessy, Kara Madden and Jeannine Webster and the launch of the paper “Who cares? The Carers Perspective for Psychiatrists”.

2013

Winter Conference: Grand Hotel, Malahide, Co Dublin: Brian McNulty, John Kidney and Diarmuid Ring presented the paper, “On the One Road to Recovery”.

CPsychI Summer School

2014

‘Changing hearts and Minds’

Brian McNulty presented in Cork and Galway
George Bridges presented in Dublin

2013

Presentation in Dublin and Galway

2012

Lisa Butterly presented at the Summer School in Dublin

Med Fest

2014

Vivienne Dick took part as a member of the panel in NUI Galway

Committees:

2014

John Dixon and Julie Healy/Angela Dixon-Member of the External Affairs and Policy Committee
John Kidney-Member of Committee for the Think Tank Newsletter for College Trainees
Julie Healy and Collette Fahy- Theme steering group, “Caring for Carers”

2013

John Casey- Editorial Board Member of the Irish Journal of Psychological Medicine (IJPM)

Mock Exam for College Trainees

2014

Liam Hennessy and Christine McCabe were invited to observe the mock oral examinations

Spike Milligan Public Speaking Competition

2014

Christine McCabe sat on the judging panel along with Chair of the College Trainee Committee, Gearóid Moynihan and consultant adult psychiatrist, Finian O'Brien.

Appendix 5.

Presentations by CPsychI members to REFOCUS

2012

Prof Greg Swanwick, Dean of Education gave a presentation on newly formed training processes in the College which was established in 2009. After intern year, a doctor who chooses to specialise in psychiatry will spend four years on a basic specialist training scheme, and at the end of that they complete an exam in psychiatry.

Dr Karen O'Connor, a higher specialist trainee gave a presentation on her own training past, including what she liked about psychiatry and her time in Australia with Orygen Youth Health Clinical Program.

Both were very positive about REFOCUS and how it could be involved in training.

Dr Anthony McCarthy, President of the College gave a personal account of his journey in psychiatry. He then spoke of his training in psychoanalytical psychotherapy. He referred to the need for all psychiatrists to have good basic communication skills. He spoke of the different types of counselling and psychotherapy that are available. He stated that a psychiatrist requires a good knowledge of these therapies, in order to refer individuals, and also to be able to assess the impact the therapy is having on the patient. He was very positive about the work of REFOCUS.

Dr Mary Clarke, Ms Elizabeth Lawlor and Mr Patrick Egan of DETECT gave a presentation of their service for those with a first episode of psychosis, and engaged in an informative interactive Q&A discussion. They invited members for certain future projects.

2013

Dr Anne Jeffers gave a brief outline of the role of the College's External Affairs and Policy department. There was particular interest in the papers the College develops and how the College approaches media involvement and work with external organisations. ECT was an area of particular interest; many people expressed an interest in hearing more about this.

Dr Consilia Walsh, Treasurer of the College presented on ECT. She described how it works, why it is still used, the changes in regulation and administration over thirty years until now. It was agreed it would be helpful to have a paper from REFOCUS commenting on the College ECT position paper and perceptions of ECT.

Dr Mary Clarke and Mr Patrick Egan from DETECT gave a presentation on service user research. Dr Clarke spoke of the possibility of using more qualitative rather than quantitative research. Mr Egan spoke of the work he has been involved with in family education. He referred to the resilience of families, and how many families developed their own coping strategies. They are looking at the impact and use of education; the impact of training family members on motivational interviewing, and families teaching others how to manage conflict.

Prof Brendan Kelly, Chair of the College Law Committee presented on Human Rights and the Mental Health Act. There were a number of interesting questions and comments, which ranged from concerns about poor services, to the benefits of using authorised officers. The Convention on the Rights of Persons with Disability was discussed and the advantages and disadvantages of mental health being classified as a disability. He was very interested to hear REFOCUS members view on advance directives and how they might work. He is also the Editor of the College's journal, the Irish Journal of Psychological Medicine and invited a REFOCUS member to join the editorial board.

2014

Dr Pat Devitt, Inspector of Mental Health Services, presented on his role as Inspector and that of the Inspectorate. He spoke of how his vision is that of '*A Vision for Change*', particularly the principle of Recovery. He explained that, where there is an imbalance of power, there must be some mechanism to ensure there is not an abuse of that power. He also spoke on the history of inspections in institutions.

Dr Jogin Thakore, Consultant Psychiatrist St Vincents Hospital Fairview presented on physical illness in those with mental illness in an interactive way enabling questions and some discussion which REFOCUS found very informative.

Appendix 6.

External Activities and Actions

2014

Consumer and Carer Curriculum Review at St John of God Hospital

Kara Madden and George Bridges joined a meeting to discuss a review of the undergraduate curriculum in mental health for pharmacists at the Royal College of Surgeons.

Collaboration with DETECT

Following presentations from Dr Mary Clarke and Pat Egan of DETECT, REFOCUS member Vivienne Dick was invited to take part in an advisory group as part of a new project which hopes to address the expressed needs of families. This project has been running for about nine months and is based around serving the needs of the family through education courses. REFOCUS member George Bridges is now working with DETECT as part of the advisory group. This work will continue throughout 2015.

Review of the Mental Health Act

Following an invitation from the Minister of State for Mental Health, Ms Kathleen Lynch TD, carer/family members met with the Mental Health Unit of the Department of Health. Jeannine Webster, Vivienne Dick, John Casey and Julie Healy, with Andrea Ryder and Anne Jeffers, attended a meeting for a comprehensive discussion based on key questions.

Referenced by SHINE paper 'Realising family friendly mental health services' and cited on SHINE website

2013

EUFAMI Conference 'A Perfect Vision for Mental Health 2020'

REFOCUS had a presence at this conference. Christine McCabe and Colette Fahy represented the group and networked with a number of other groups from a REFOCUS stand which was positively received. The 'Who Cares' paper was available and a poster was displayed outlining the ten themes in the paper.



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www.irishpsychiatry.ie

www.irishpsychiatry.ie/Ext-Affairs-Policy/REFOCUSCPsychI.aspx