

**MEMORY ASSESSMENT AND RESEARCH CENTRE (MARC)****RESULTS OF THE 2012 “MARC FEEDBACK QUESTIONNAIRE” AUDIT**

## AIMS:

1. To find out patients and study partners' views on the service provided by MARC to enable us to identify areas of our practice that have improved since 2011 and those which require review and attention.(Qs 1-5.)
2. To elicit patients and study partners views on participating in research. (Qs 6 - 8.)
3. To form an action plan to address the problems identified and to evaluate the response to these actions, either in next year's survey, or other departmental audits.

## METHOD:

1. The questionnaire used in the 2011 survey was amended to try and elicit relevant information in an efficient way.
2. Questions one to five were asking for a tick in one of five boxes, where 5 represents “excellent” and 1 represents “poor”. Questions one to five were asked in exactly the same format in the 2011 survey, and so we can make comparisons.
3. Questions six to eight asked for a narrative response. These were not in the 2011 survey and hence no comparisons are possible.
4. All patients and their study partners attending MARC in the second half of February 2012 were asked to complete this questionnaire.
5. The responses were collated and analysed, as recorded below.
6. The MARC team will review the results and form and implement an action plan.
7. A repeat survey/ audit will be done in February 2013.

## RESULTS:

- 25 replies, 10 from patients, 15 from study partners.
- Summary and analysis of results:

## Q.1: HOW WOULD YOU DESCRIBE THE QUALITY OF THE SERVICE PROVIDED BY MARC?

## SUMMARY:

- 10/10 patients rated the quality of the service provided by MARC as excellent. (2011: rating 2= 1, rating 4=3, rating 5=17.)
- 15/15 study partners also rated the quality of the service as excellent. (2011: rating 1=1, rating 4=2, rating 5=23)

## CONCLUSION:

- The MARC team are aiming for a standard of 80% in the 4 and 5 rating categories.
- The standard met for patients has improved from 95% in 2011 to 100% in 2012.
- The standard met for study partners has improved from 96% in 2011 to 100% in 2012.
- I.e. standards have been met in 2012. No specific areas of practice requiring actions for improvement have been identified by this question.



## Q.2: HOW APPROACHABLE DID YOU FIND THE STAFF FROM MARC?

### SUMMARY:

- 10/10 patients regarded staff as being very approachable. (2011: rating 2=1, rating 5=20).
- 15/15 study partners regarded staff as being very approachable. (2011: rating 1=1, rating 5=25.)

### CONCLUSION:

- MARC is aiming for a standard of 80% in the 4 and 5 rating categories.
- The standard met for patients has improved from 95% in 2011 to 100% in 2012.
- The standard met for study partners has improved from 96% in 2011 to 100% in 2012.
- I.e. standards have been met in 2012. No specific areas of practice requiring actions for improvement have been identified by this question.

## Q.3: HOW EASY WAS IT TO ACCESS OUR SERVICES?

### SUMMARY:

- 7/10 patients regarded the ease of access to MARC as being “excellent.” (2011: rating 1= 1, rating 2= 1, rating 3= 2, rating 4= 2, rating 5= 13.)
- 3/10 patients regarded the ease of access to MARC as slightly below excellent (4/5).
- 15/15 study partners regarded the ease of access to MARC as being “excellent.” (2011: rating 1=2, rating 2=2, rating 3=1, rating 4=4, rating 5= 17.)

### CONCLUSION:

- MARC is aiming for a standard of 80% in the 4 and 5 rating categories.
- The standard met for patients has improved from 79% in 2011 to 100% in 2012.
- The standard met for study partners has improved from 81% in 2011 to 100% in 2012.
- Although we met the standard in this regard for patients, there were 3 patients who rated this 4, which could be improved on.
- This will be addressed in the action plan and the response will be evaluated in the 2013 survey.

## Q.4: OVERALL, HOW SATISFIED WERE YOU WITH THE CARE YOU AND YOUR STUDY PARTNER RECEIVED?

### SUMMARY:

- 9/10 patients regarded the overall standard of care they received as “excellent.” (2011: rating1=1, rating4= 2, rating 5=17.)
- 1/10 patient regarded the overall standard of care as slightly below excellent (4/5), but still good.
- 15/15 study partners regarded the overall standard of care as “excellent.” (2011; rating 2=1, rating4=4, rating 5=21.)

## CONCLUSION:

- MARC is aiming for a standard of 80% in the 4 and 5 rating categories.
- The standard met for patients has improved from 95% in 2011 to 100% in 2012.
- The standard met for study partners has improved from 96% in 2011 to 100% in 2012.
- Although we met our standard, we would still like all patients to feel very satisfied (5) with the care they received.
- However, this is difficult to address in a specific way, because we do not know in what specific way we failed to deliver excellent care to that one patient.
- Therefore, the form for the 2013 survey needs to be amended to ask an additional question: "If the care is not regarded as excellent, please tell us what specific aspect of care we could improve on."

## Q.5: DO YOU FEEL YOU RECEIVED SUFFICIENT INFORMATION ABOUT YOUR CARE?

### SUMMARY:

- 9/10 patients felt that the amount of information they received about their care was sufficient/excellent. (2011: rating 1=1, rating 4=2, rating 5=17.)
- 1/10 patients felt that the amount of information they received about their care was good (4/5) but not excellent.
- 15/15 study partners felt that the amount of information they received was sufficient/excellent. (2011: rating 2=1, rating 3=1, rating 4=3, rating 5=20.)

## CONCLUSION:

- MARC is aiming for a standard of 80% in the 4 and 5 rating categories.
- The standard met for patients has improved from 95% in 2011 to 100% in 2012.
- The standard met for study partners has improved from 92% in 2011 to 100% in 2012.
- I.e. standards have been met in 2012. No specific areas of practice requiring actions for improvement have been identified by this question.

## Q.6: WHAT MADE YOU DECIDE TO TAKE PART IN A CLINICAL RESEARCH TRIAL?

1. "My wife was phoned by her physiotherapist at Winchester Hospital to say her aunt in London was on a new drug, which had made her feel a new person. Spoke to our team Anna Mould, Newtown House. She said no new drug. Most probably was a drug trial. I said please let me join any of the drug trials." – *Patient (P)*.
2. "Hoping to help."- *Study partner (SP)*.
3. "My mother and I thought that it may help people in the future to get a cure for the condition." – *SP*.
4. "To help others if not ourselves." – *SP*.
5. "To find out about dementia." – *P*.
6. No response. – *SP*.
7. "To help others in the future." – *P*.
8. "The prospect of receiving a trial drug that would improve (my partner's) condition; or if part of control group, helping to find a cure for this dreadful illness (Alzheimer's.)" – *SP*.
9. "Persuasion by husband to join." – *P*.
10. "Hope." – *SP*.
11. "Hope." – *P*.
12. "We hoped it would make my wife better and have use for others." – *SP*.
13. "Looking for treatment that would slow the progress of the disease." – *SP*.

14. "To help other future sufferers." – *P*.
15. "To help other future sufferers." – *SP*.
16. "Possible future benefit." – *SP*.
17. "After being approached about the research, thought it would be a helpful experience, both to myself and others." – *P*.
18. "To help my husband to take part in anything that may be of help to him." – *SP*.
19. "When we were aware of the trials, we thought that at our ages, we hoped to be able to contribute something to help future generations." – *SP*.
20. "A feeling of hope that my husband may have some benefit and if not perhaps other people may benefit." – *SP*.
21. "It seemed a reasonable way to offer something back." – *P*.
22. "Concern about my failing memory." – *P*.
23. "Hopefully to help my husband in the future." – *SP*.
24. "To help with further development of the drug." – *P*.
25. "Nothing much was being done apart from Aricept which didn't help at all, so was stopped." – *SP*.

#### SUMMARY:

It is acknowledged that each statement stands alone, but as far as one can summarise, the answers have been classified as "for altruistic reasons" or "to get help for self" or "to get help for partner". Some answers express both concepts.

- 10/15 study partners. – *Altruistic reasons*.
- 8/15 study partners. – *To get help for partner*.
- 5/10 patients. – *Altruistic reasons*.
- 6/10 patients. – *To get help for self*.

#### CONCLUSION:

The findings are in keeping with anecdotal evidence. This question is interesting, but it does not necessarily help us to improve the service and so it will be omitted from the 2013 survey.

#### Q.7: HOW DID YOU FIND OUT ABOUT MARC?

1. "Newtown House." – *P*.
2. "By asking about clinical research." – *SP*.
3. "Via a doctor who we visited there." – *SP*.
4. "We were contacted by this department." – *SP*.
5. No response. – *P*.
6. No response. – *SP*.
7. "Moorgreen Hospital." – *P*.
8. "Via Karen Cotton, memory nurse." – *SP*.
9. "Via Karen Cotton, memory nurse." – *P*.
10. "From appointment at memory clinic." – *SP*.
11. "From appointment at memory clinic." – *P*.
12. "Southampton General and GP." – *SP*.
13. "Through contact with our local Alzheimer's Association." – *SP*.
14. "Diagnosed at Moorgreen." – *SP*.
15. "Diagnosed at Moorgreen." – *P*.
16. "Community Psychiatric Nurse." – *SP*.
17. "From one of the assessors, June Salked." – *P*.
18. "From June Salked." – *SP*.

19. "Through a friend in Winchester Hospital who spoke of her aunt in London being on a new drug, spoke to Anna Mould, Newtown House, who said it was probably drug trials." – *SP*.
20. "Through memory clinic at Andover War Memorial Hospital." – *SP*.
21. "I forget who suggested it..." – *P*.
22. "From the Andover memory clinic." – *P*.
23. "Memory nurse visit." – *SP*.
24. "Through a memory nurse." – *P*.
25. "Through Karen Cotton..." – *SP*.

#### SUMMARY:

- 2 self-referrals.
- 8 referrals from other healthcare professionals (7 local i.e. Southampton area, 1 from Andover.)
- 1 referral from case-load mining. (?)
- 4 through traditional MARC memory clinic.

#### CONCLUSION:

- Although these results are not statistically significant in any way, they suggest a gradual change from the situation reflected in the June 2011 audit of referrals to MARC, where 52.5 % of referrals were from the traditional MARC route, 30 % from other health care professionals within the Trust and 17.5 % from other health care professionals outside the Trust. There were no self referrals or referrals arising from case-load mining.
- I.e. there is a shift towards more referrals being made by local HCPs, which is welcome.
- One referral may have arisen from case-load mining and the response of the study partner seems to suggest the first contact was made by a MARC team member and not by a care co-ordinator. This is not department policy and it does not meet GCP guidelines. This has been identified as an area that requires clarification, and action is being taken under the remit of the development of an ethically sound, efficient and sustainable recruitment strategy for MARC.
- The information arising from this question, Q.7 will now be captured in the rolling audits being done as part of the recruitment strategy, and so this question will be omitted from the 2013 survey.

#### Q.8: DID YOU ENJOY THE EXPERIENCE AND WOULD YOU RECOMMEND IT TO OTHERS?

Note: Due to a proof-reading error, the phrase "Did you enjoy the experience ...." was included, instead of "Are you pleased you took part in research ...." This question will be amended accordingly in the 2013 survey.

1. "Yes, a very positive experience. I would certainly recommend (it) to others." – *P*.
2. No response. - *SP*.
3. "Yes the experience was very positive and I would recommend it to others." – *SP*.
4. "Yes." – *SP*.
5. No response. - *P*.
6. No response. – *SP*.
7. "Yes." – *P*.
8. "It's a drug trial, not a west end show, so not easy to answer! It gives us an opportunity to get (my partner) motivated to go out. So I would recommend it to others in a similar situation. – *SP*.
9. "Yes. I enjoy meeting others and I would recommend (it) to others." – *P*.

10. "?" (For "pleased" phrase) and "I would recommend it to others." – *SP*.
11. "?" (For "pleased" phrase) and "I would recommend it to others." – *P*.
12. "Not sure about enjoy! But would recommend it." – *SP*.
13. "The experience has been well organised and friendly and I would recommend it to others to participate." – *SP*.
14. "Yes." – *SP*.
15. "Yes." – *P*.
16. "Definitely." – *SP*.
17. "Enjoyed the experience and would heartily recommend it to others." – *P*.
18. "Yes and would recommend to others." – *SP*.
19. "Yes and would certainly recommend to others." – *SP*.
20. "We would recommend the experience to others." – *SP*.
21. "The simple answer is "yes" and "yes"...." – *P*.
22. "Enjoy is not quite the right word!! However, I feel that, at least, it may help me and others." – *P*.
23. "Yes." – *SP*.
24. "Yes." – *P*.
25. "Really enjoyed it, it's nice meeting other carers, my partner has definitely improved, much happier and enjoys chatting to others now. No improvement to short term memory so far. Would definitely recommend it to others." – *SP*.

#### SUMMARY:

- 7 patients said that they "enjoyed the experience", 2 pointed out it was a silly question and one did not respond, hence one can conclude that 7/9 (78%) of patients who responded said that they enjoyed the experience.
- 8 patients said they would recommend it to others, one did not respond and one did not answer that specific question, hence one can conclude that 8/8 (100%) of patients who responded to the question would recommend participating in research to others.
- 10 study partners said that they "enjoyed the experience", 2 did not respond and 3 pointed out that it was a silly question to ask. Hence one can conclude that 10/13 (77%) of study partners who responded to the question said that they enjoyed the experience.
- 13 study partners said that they would recommend it to others and 2 did not respond, hence 13/13 (100%) of study partners who responded to the question said that they would recommend participating in research to others.

#### CONCLUSION:

- Despite the poor choice of the "enjoy" phrase, 78% of patients and 77% of study partners said they enjoyed the experience.
- We have set a standard of 80%, so we have not met the standard, but this may be due to the choice of wording.
- This phrase will be amended in the 2013 survey, as already discussed.
- 100% of patients and 100% of study partners would recommend participating in clinical research trials.
- The standard of 80% has been met.
- This question is in fact 2 questions, and will be separated into 2 tick box questions in the 2013 survey.

ACTION PLAN:

PROBLEM	ACTIONS	BY WHOM	BY WHEN	RE-AUDIT RESULT EXPECTED
1. 3/10 patients regarded the ease of access to MARC as below excellent (4/5), but still good.	<p>Develop and implement a recruitment strategy aimed at increasing the profile of MARC amongst the public and other HCPS.</p> <p>In order to avoid confusion about whether this question is referring to physical access to the unit, question 3 will be amended for the 2013 survey, to "How easy was it to become involved in research?"</p>	<p>Whole team and DeNDRoN.</p> <p>Dr Sharples</p>	<p>Ongoing.</p> <p>Done</p>	Std.: 80% ratings 4 and 5.
2. 1 patient out of 10 regarded the overall standard of care as below excellent (4/5), but still good.	<p>This is difficult to address in a specific way, because we do not know in what specific way we failed to deliver excellent care to that one patient.</p> <p>Therefore, the form for the 2013 survey needs to be amended to try and elicit specific problems.</p>	Dr Sharples.	Done	Std.: 80% ratings 4 and 5.
4. Despite the poor choice of the "enjoy" phrase, 78% of patients and 77% of carers said they enjoyed the experience and there were no negative responses. This phrase will be amended in the	This phrase will be amended in the 2013 survey, to a single question: "Are you pleased you took part in a clinical research trial?"	Dr Sharples	Done	Std.: 80%.

2013 survey, as already discussed.				
5. The amended questionnaire must be reviewed by the whole team to check that it is fit for purpose.	E-mail a draft of an amended questionnaire to the whole team and then decide on a final version at a team meeting on 23.5.12.	Dr Sharples and whole team.	Done.	N/A
6. The numbers in the 2012 survey were low in comparison to the 2011 survey.	Aim to extend the time of the survey to the whole of February and March in 2013.	Whole team.	March 2013.	Aim for an increase of 50% (n=15 for patients, n=23 for carers.)
7. Following the presentation to the team on 23.5.12, it was felt that the results of the survey are positive and interesting and should be more widely circulated.	Send a copy of the final report to Jamie Stevenson of the Trust communications department for local dissemination and a copy to David Higenbottam for wider dissemination.	Dr Sharples	June 2012	N/A

COMMENT BY DR WIKINSON, OUT-GOING DIRECTOR OF MARC:

Although the numbers were small, the feedback is remarkable, especially as this represents “added value” to patients with a terminal disease when the NHS is under real pressure to improve quality of care. The improvement in 2012 may reflect that the current trials involve patients with milder degrees of cognitive impairment than the trials that were being done in 2010/2011, but even so, the target standard of 100% being reached so many times suggests the experience is as positive as it can be for patients and carers.

This survey shows that research is not simply for the researchers and that patients and carers feel a real sense of altruism and giving something back to help future generations, as well as the real positive health benefits from being involved in clinical research.

This echoes very much the national priority to give everyone with a diagnosis of Alzheimer’s Disease the opportunity to take part in clinical research. This not only furthers the prospects of finding new treatments and keeping services at the cutting edge of knowledge, but improves the well-being of patients and carers, giving them hope and a sense of control over the illness that they would otherwise lack.