

Scottish Society for Rheumatology

Patient Experience Survey 2018

From October 2017 to February 2018 SSR asked centres to participate in a Patient Experience Survey. The anonymised survey sought feedback on ten dimensions; needs and preferences, coordination of care, information education and self-care, daily living, emotional support, family and friends, access to care, review, work and overall experience. 793 responses were received from 9 centres across Scotland. Thank you to all who contributed to the survey - this will be very valuable information and will help us improve care for patients in Scotland with RA.

Summary of responses

1. Needs and preferences

A positive 78.9% of respondents strongly agreed that they were treated respectfully as an individual at clinic, with responses predominantly strongly agreeing/ agreeing across all of the needs and preferences dimensions.

Needs and Preferences (%)	Strongly agree	Agree	Neither	Disagree
a. Whenever I attended clinic I felt that I was treated respectfully as an individual	79	18	0	-
b. I was actively involved as much as I wanted in decisions about my care	69	25	3	0
c. My personal circumstances and preferences were understood and taken into account when planning and deciding on my treatment and care	63	27	5	1
d. I was given information in a way that I could understand	69	26	2	-
e. I was given enough information to help me make decisions about my care	65	27	3	1

2. Coordination of Care

Again largely positive feedback, with respondents agreeing or strongly agreeing on the level of coordination of care. Responses indicate that coordination with and between primary care could be improved in addition to continuity and accessing care between appointments.

Coordination of Care (%)	Strongly agree	Agree	Neither	Disagree	Strongly disagree
a. I was given clear information about the respective roles of the team of health professionals looking after me	58	30	7	1	0
b. When I needed help between routine appointments I knew how to reach the right person to provide it	60	27	6	2	0
c. When I sought help between routine appointments I was successful in accessing it	55	27	10	3	0



d. I feel that the people I see at clinic are fully up to date with my current situation	65	27	4	0	0
e. Overall I feel I have a good understanding of what the Rheumatology team offers and how to make the most of my care	63	29	4	1	0
f. I am confident my GP has sufficient information on and understanding my condition to effectively support me	33	47	13	3	0

3. Information Education and Self Care

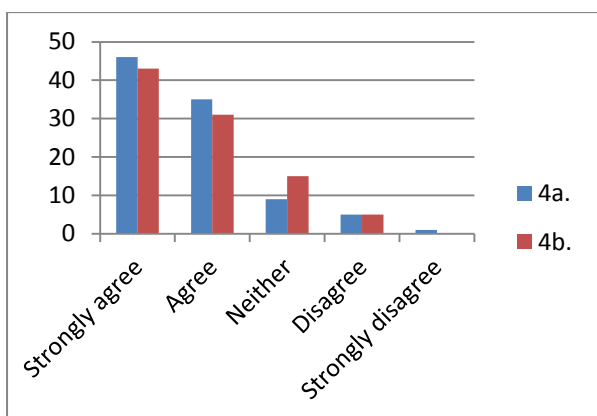
Responses indicate that opportunities for self-care via patient organisations or groups, and self-management have not been available.

Information Education and self-care (%)	Strongly agree	Agree	Neither	Disagree	Strongly disagree
a. I feel that I was given information at the time I needed it	52	35	7	2	0
b. I feel that I have a good understanding of the treatments I am on or being offered	57	37	2	1	0
c. I have been told about patient organisations or groups that can help me	31	27	21	12	1
d. I have been offered an opportunity to attend a self-management programme suitable to my needs	21	17	28	22	2

4. Daily Living and

a. 46% of respondents feel that their rheumatoid arthritis is being controlled enough to let them get on with my daily life.

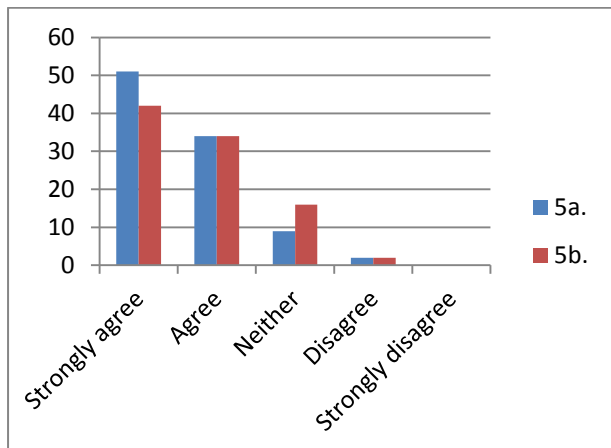
b. 43% strongly agree that they have been able to get help quickly in the event of a flare up.



5. Emotional Support

a. 51% of respondents strongly agree they have felt able to approach a member of their health team to discuss about condition and treatment worries.

b. 42% of respondents strongly agree that they have felt able to discuss personal or intimate issues about relationships with their health team.



6. Family and Friends

83% agree/ strongly agree that they feel able to involve family members in decisions.

Family and Friends (%)	Strongly agree	Agree	Neither	Disagree	Strongly agree
a. I feel able to take members of my family to outpatient appointments to become involved in decisions	49	34	13	1	0

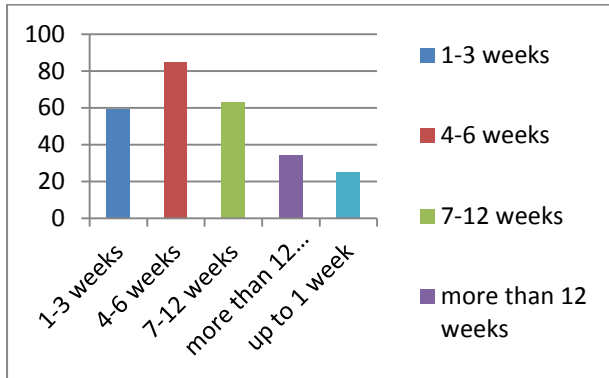
7. Access to Care

Access to Care (%)	Strongly agree/ Yes	Agree/ No	Neither	Disagree	Strongly agree
a. At appointments I feel that I have enough time with the health care professionals to cover everything I want to discuss	59	34	3	1	
d. I have needed extra support extra treatment or a change of treatment	40	42	-	-	-

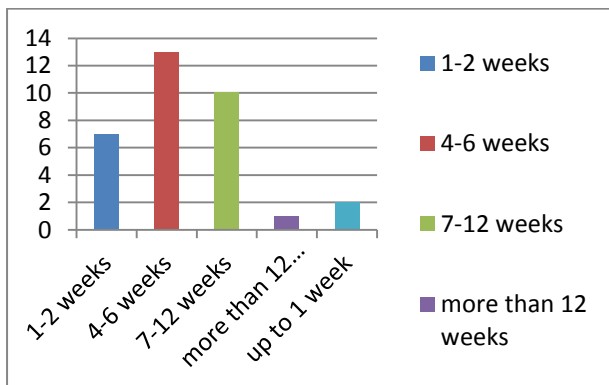
7b&c. Have you had an appointment cancelled unexpectedly?

If yes, how long have you had to wait for a new appointment?

29% of respondents have had appointments cancelled unexpectedly. Of those whose appointments were cancelled unexpectedly, 85 had to wait 4-6 weeks for a new appointment.

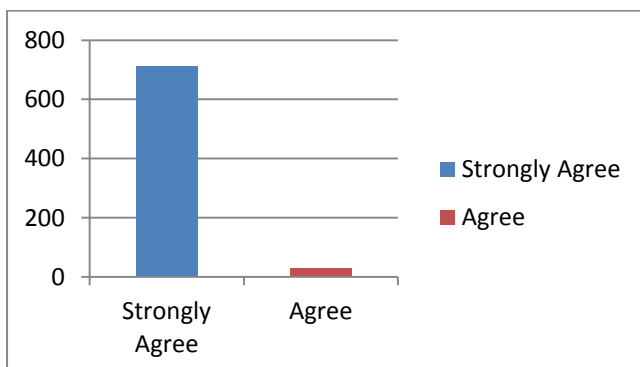


7e. If yes, how long did it take to get an appointment at which support/ treatment offered?



8. Review

90% of respondents have an annual review with their consultant or other team member at which condition and general health is discussed.



9. Work

Responses to work/ employment status and desire to explore possibilities of working are summarised below.

Work	%
a. I work and the rheumatology team recognised the need to take this into account in my treatment and care	45
b. I do not work at present but wish to explore the possibility of working	6
c. I do not feel able to work at present on account of my condition	20
d. I do not work for reasons unrelated and do not wish to explore the possibility	29

10.

Overall in the past year, 91% of respondents agreed that they have had a good experience of care for their rheumatoid arthritis.

