

Patient and carer experience of joint renal and palliative care nurse led clinics

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Background to the joint clinics

- National Framework for Renal Services (2005);
- Joint renal and palliative care nurse led clinics commenced in 2007 at the Royal Free NHS Foundation Trust;
- Joint clinics now run in the 4 satellite units.

Referral Criteria

1. eGFR = 15ml/hr or less
2. Advance care planning
3. Complex symptom control
4. Psycho-social support required

Interventions Offered

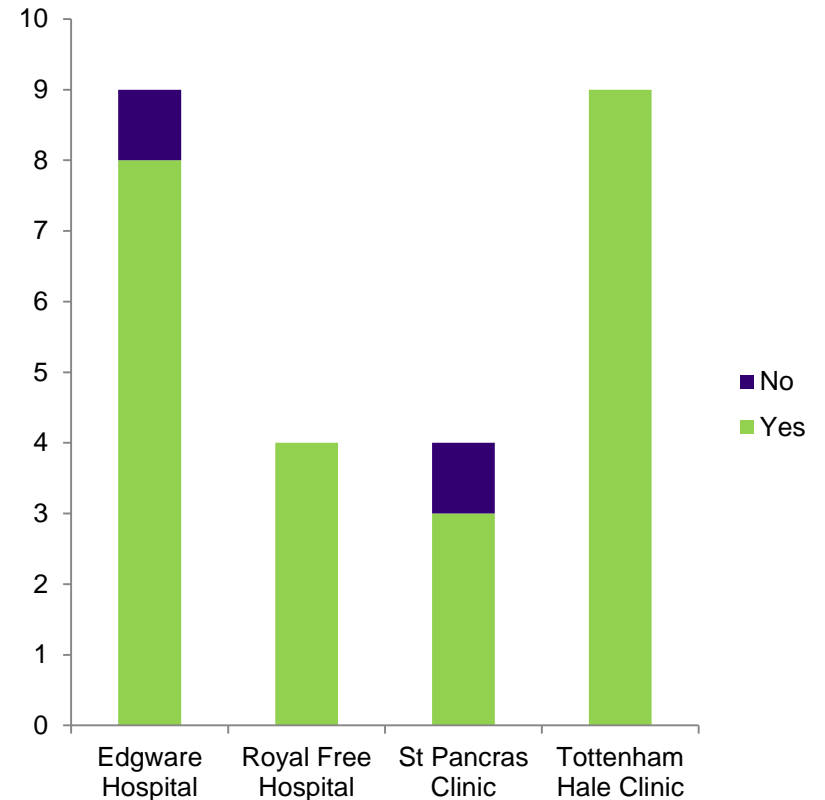
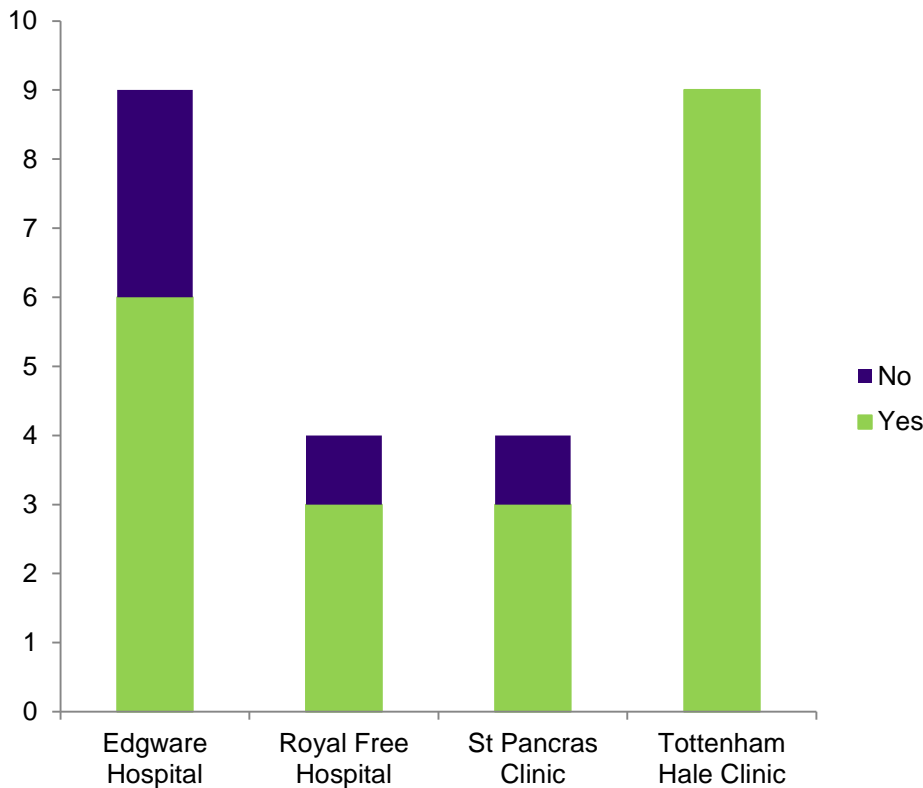
- To ascertain the patient's concerns, values and personal goals for care;
- To establish patient's preference for types of care and treatment including their views on ceilings of treatment;
- To provide an opportunity to create an advance statement of their wishes or an advance decision to refuse treatment (ADRT);
- To ensure that relevant health care providers, including, out of hours services and emergency services are aware of the patient's wishes;
- To offer complex symptom control advice and psycho-social support;
- Carer support including for those patients with limited capacity.

Patient and carer experience survey

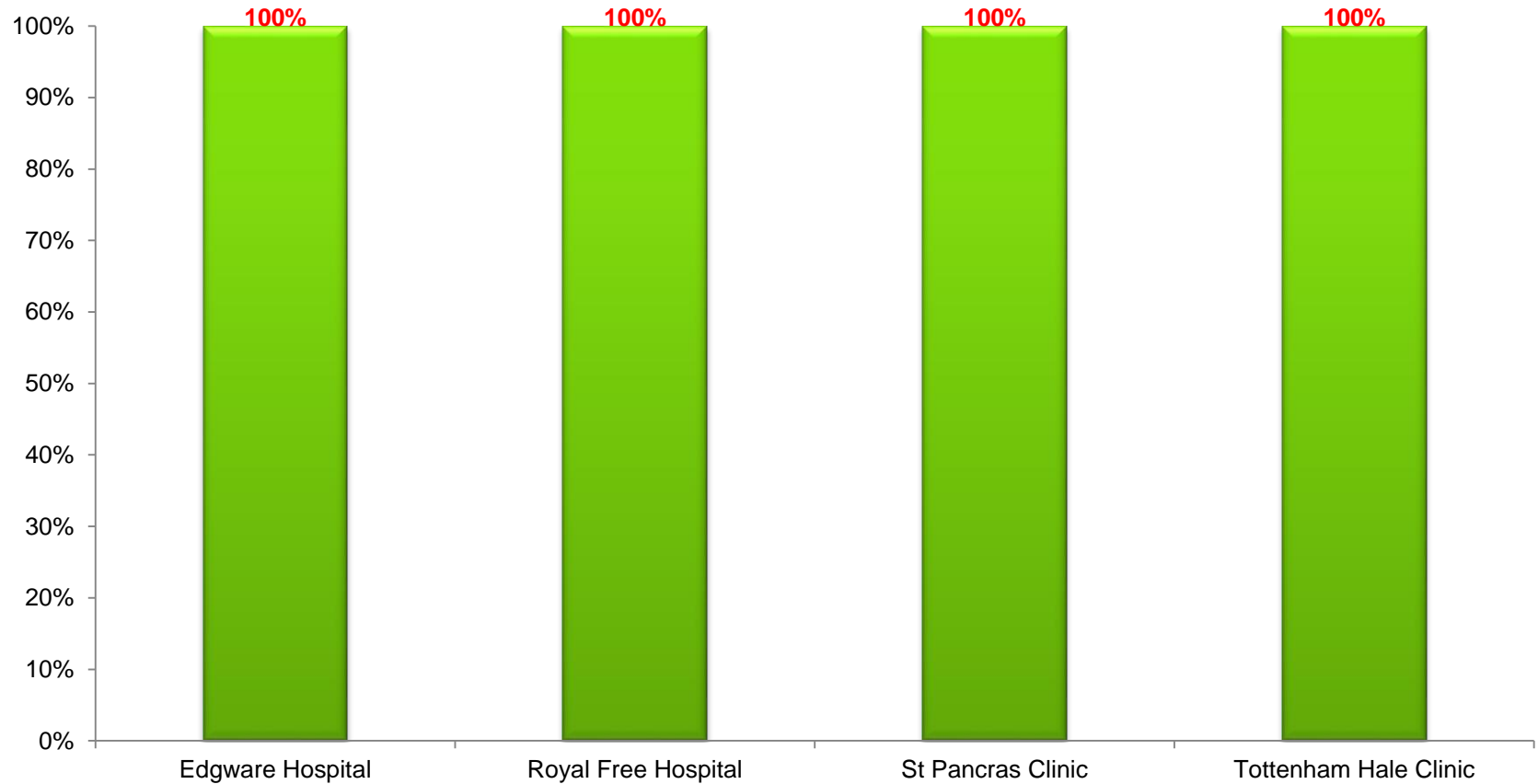
- 55 questionnaires distributed over a 1 year period (July 2016-July 2017);
- Postal and face-to-face distribution;
- Includes all new and existing joint clinic patients;
- Patient **and** carer experience survey to learn from both perspectives;
- Anonymised questionnaires;
- Questions based on interventions offered (as per operational policy)
- 47% response rate (53% of these replies has comments from carers).

Did you know that you were going to be referred to the joint clinic?

Did you understand why you were referred to the joint clinic?

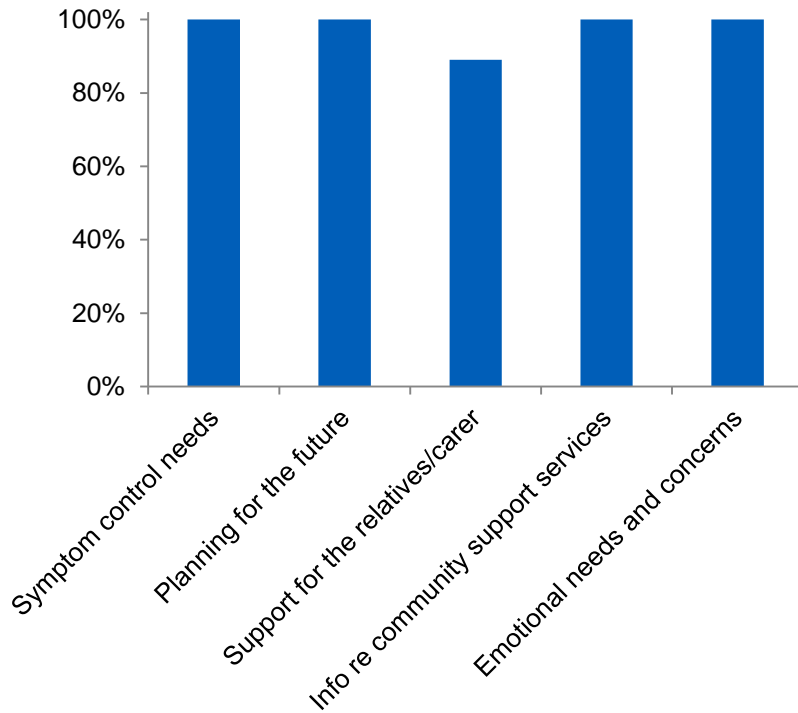


Did the nurses in the joint clinic explain their role and the purpose of the clinic?

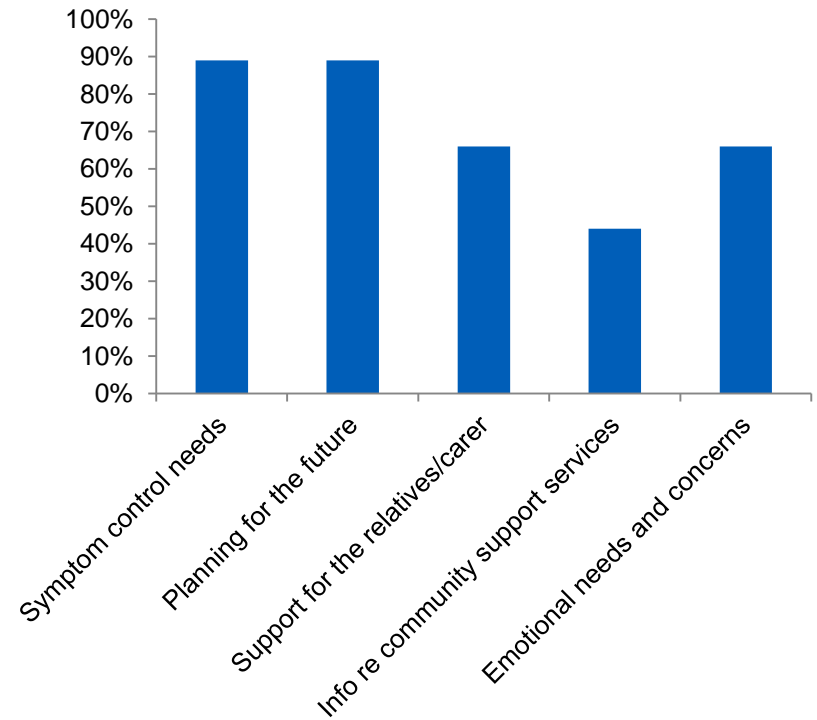


Issues that were addressed in the joint clinic

Tottenham Hale

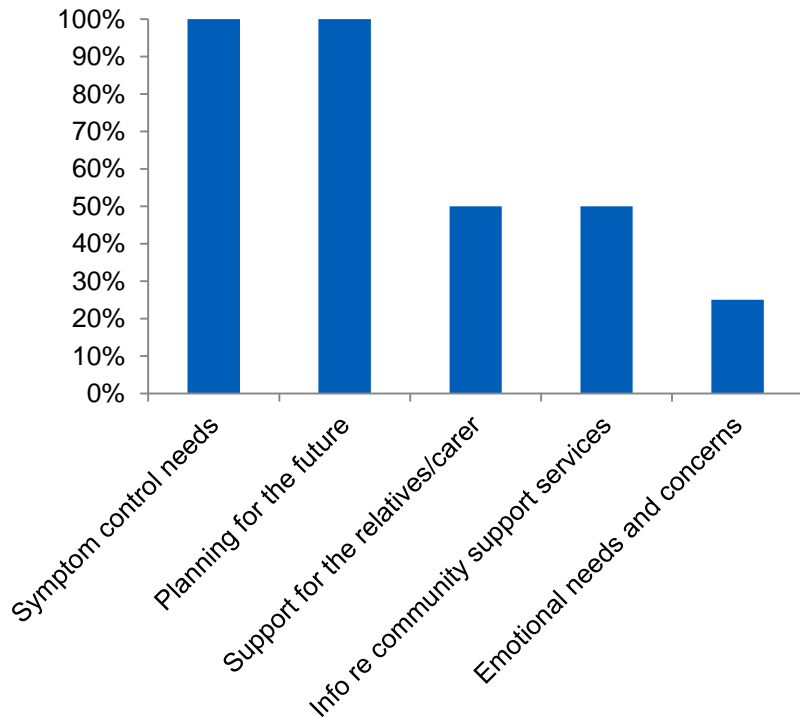


Edgware

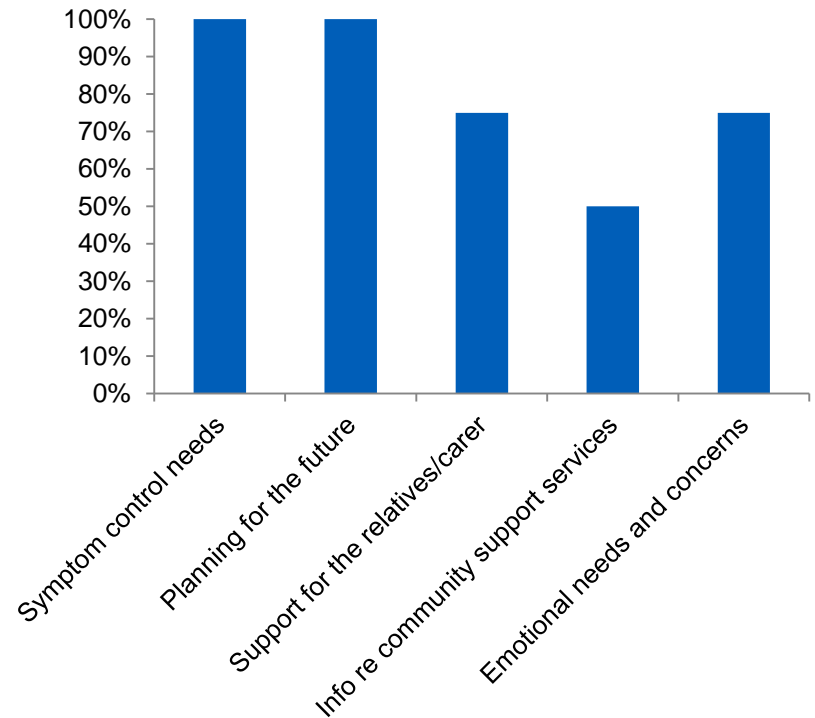


Issues that were addresses in the joint clinic

Royal Free



St Pancras



Anything else that you found useful?

positively  welcoming

actively  respectful

clearly  communicating

visibly  reassuring

'Staff take time to explain procedures'.

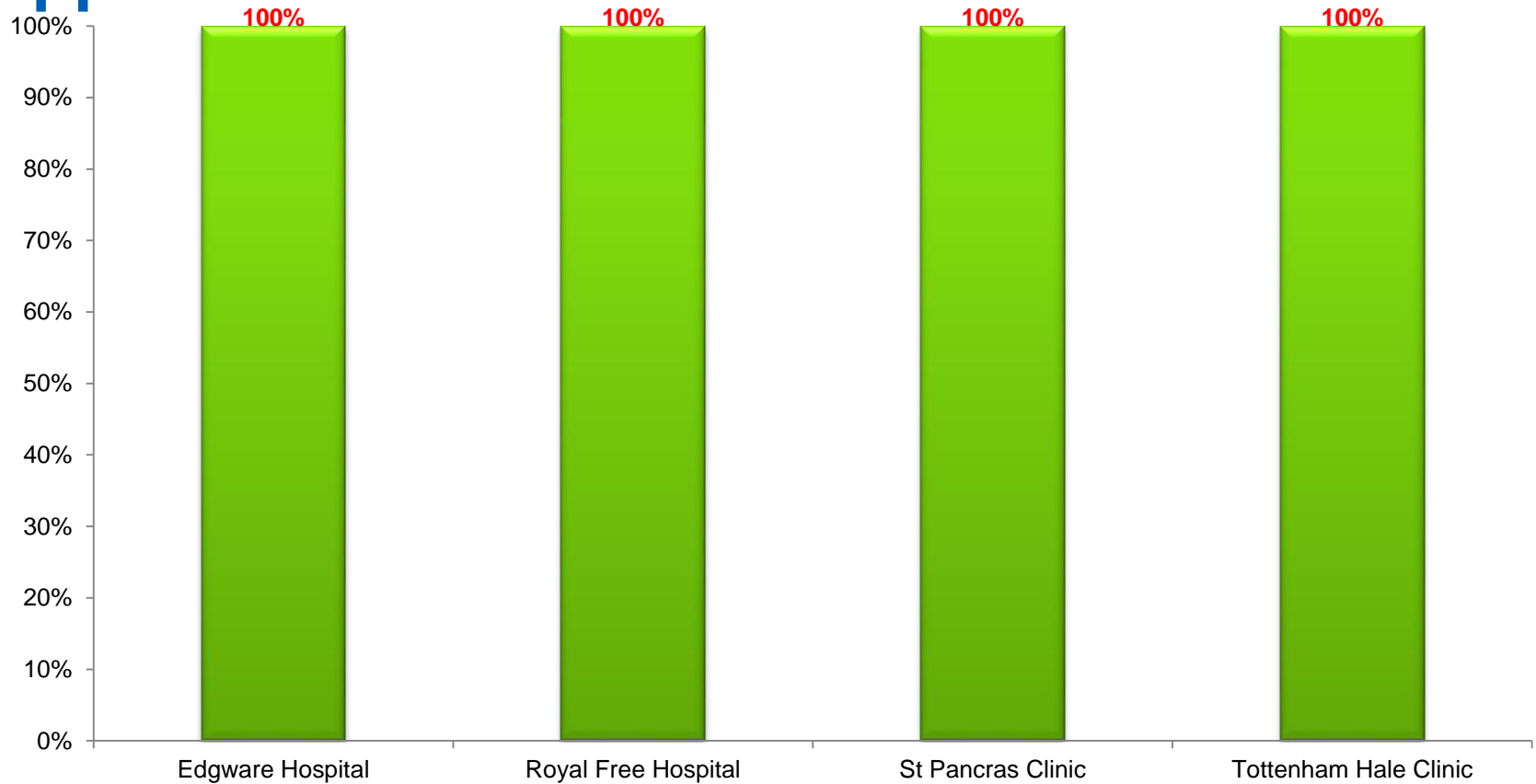
'The team consultation was productive'.

'Very thorough explanation and positive attitude'.

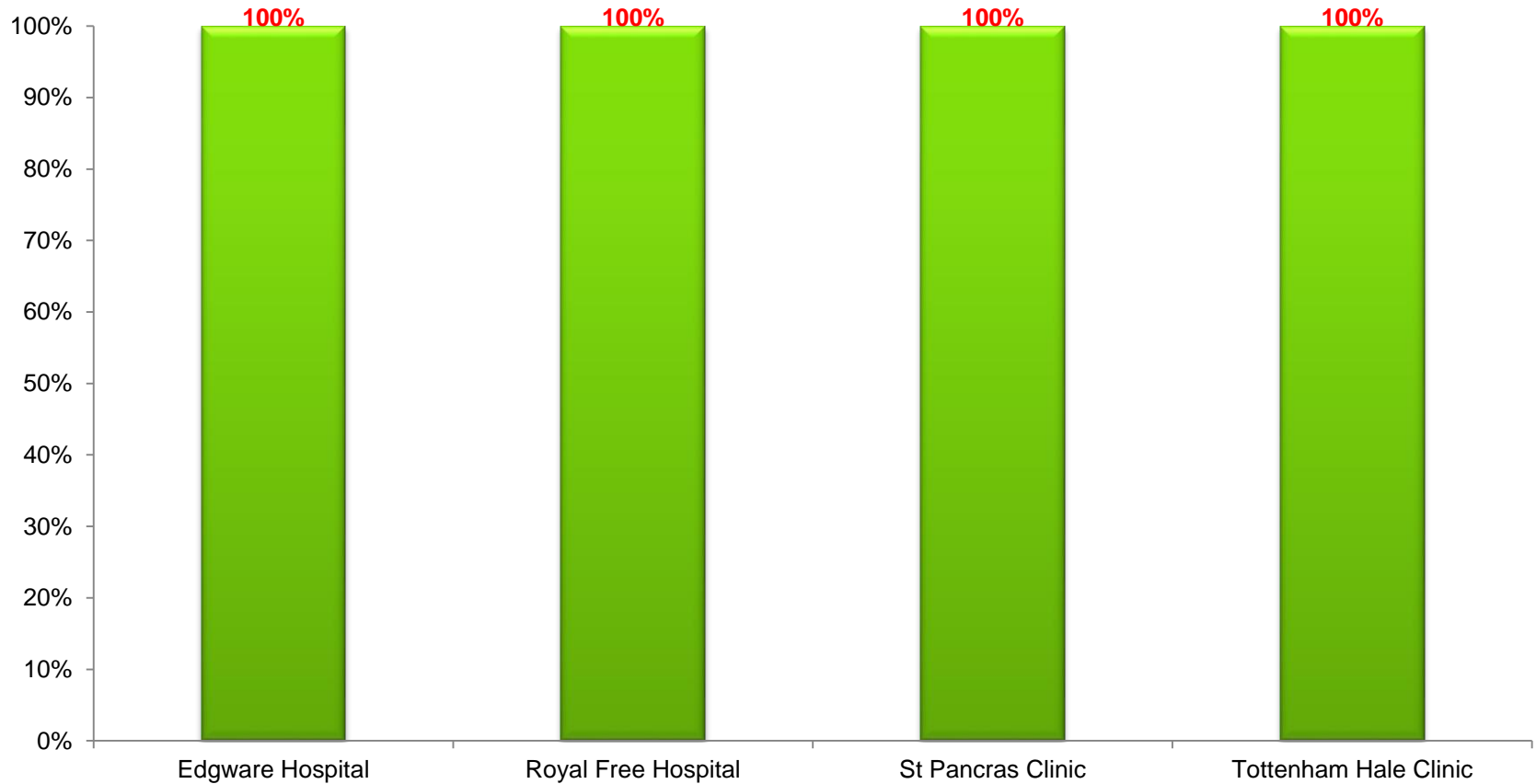
'All the staff were courteous and helpful. Keep it up'.

'Very impressed with the time and service made available to us. Explanation and service offered around co-ordinate my care re emergency services was very reassuring'.

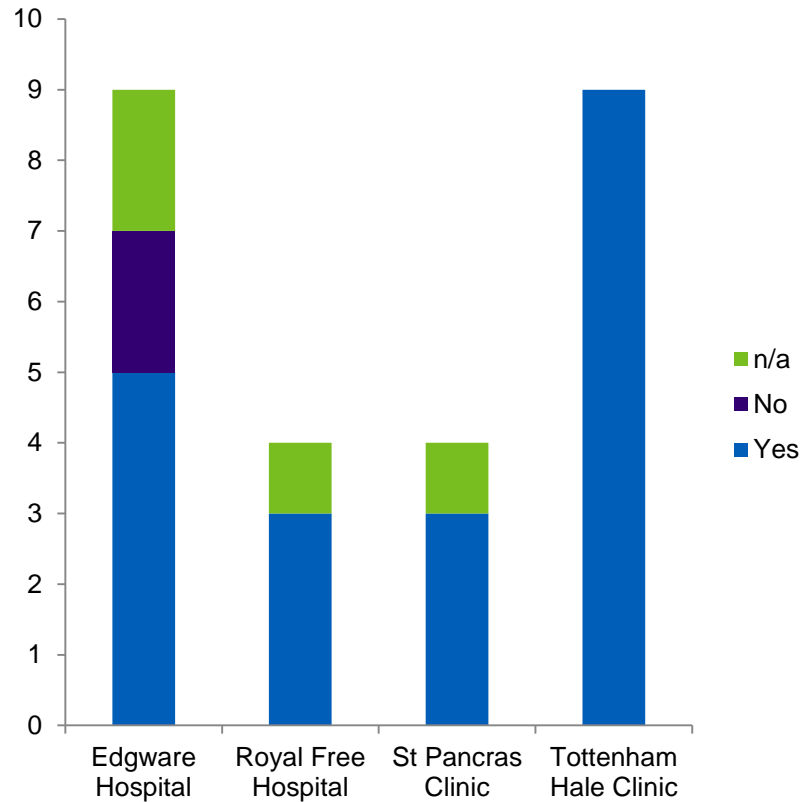
Did you have enough time to discuss your worries and concerns at the clinic appointment?



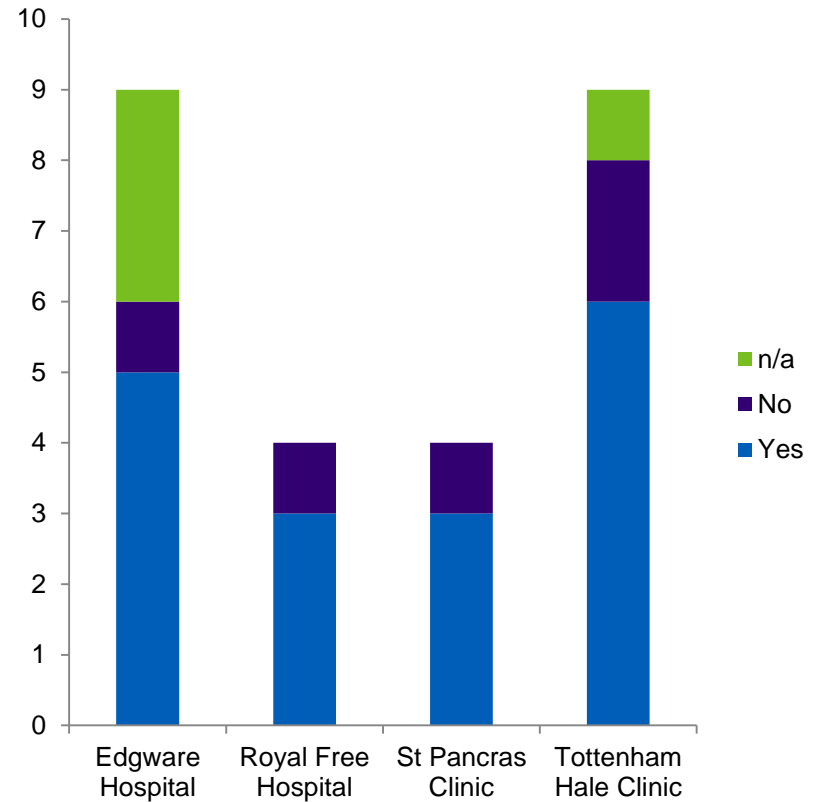
Did you feel involved in all aspects of the decision making?



Did you find the 'Planning for your future care' booklet helpful?



Where appropriate, did you find the 'my preferences for care' document and/or ADRT helpful?



‘Excellent and much appreciated and comforting approach. In a climate of NHS cuts, we really felt the service is very needed and excellent to know this is offered’.

‘I was happy about all the explanation on what care and support my mum will need when she becomes unwell’.

‘All information is explained fully and clearly. Management of patient care is very good. Patient is made to feel at ease and involved in the decision making’.

‘The nurses/staff in clinic always make my father feel relaxed and take the time to explain things even though it can take a while for my father to process information’.

Conclusions

- Generally positive feedback;
- Reiterates the need for clear explanation about the role of the clinic prior to patient referral;
- Time, information giving and choice vital components of the joint clinic;
- Feedback reflects the Trust's World Class Care Values;
- Appropriate interventions provided;
- Value of carer support.