Royal United Hospitals Bath
NHS Foundation Trust

Rheumatology Patient Initiated Follow Up Long Term Condition (PIFU- LTC)

Implementation of a Rheumatology Patient Initiated Follow Up approach

As you will be aware, at the end of July 2020, NHS England and NHS Improvement wrote to all local NHS systems to set out the third phase of the NHS response to
COVID-19. This highlighted the recovery of elective activity levels as a key priority and referenced patient initiated follow up (PIFU) as one intervention that can support this within outpatient services.

PIFU describes when a patient, or their carer, can initiate their follow-up appointments as and when required, e.g. when their symptoms or circumstances change. This helps empower patients to take control of their own care and frees up our capacity to see patients when they need it the most. You can see more information about PIFU in the NHS England Implementing Phase 3 Guidance (1).

The RUH is already utilising the PIFU approach across a number of specialties within our outpatient services and plans to further use this approach over time. Instead of routinely booking a follow up appointment for the patient at a specified point in the future, some patients will be asked to contact the hospital to request an appointment if and when they need one, e.g. during a flare-up.

PIFU for patients with long term conditions (PIFU-LTC) is the model that will be used in Rheumatology. This option means that the duration of time between routine scheduled clinic appointments is increased e.g. to 2 years rather than 1 year. Between appointments if the patient has a deterioration in their condition they can contact our department, and they will be prioritised for early review. Patients that do not contact the department will still receive a follow-up appointment, i.e. they are not discharged.

PIFU-LTC will not be suitable for all patients and the decision to put a patient on a PIFU-LTC pathway will be led by their clinician on a case by case basis, based on the patient's individual needs, circumstances and preferences.

After the patient has agreed to be on a PIFU-LTC pathway, they will receive relevant information about their condition along with symptoms to watch out for and how to book an appointment if required. As their GP, we will copy you on this information.
We hope this will also help GPs by freeing up your time and reducing the workload created by chasing up follow up appointments on behalf of your patients.

Frequently asked questions

• What does PIFU-LTC mean?

PIFU-LTC is used for patients with long term or lifelong conditions e.g. Rheumatoid arthritis or Ankylosing Spondylitis. These patients may receive many hospital appointments over the duration of their disease, often when they are well. This has time and financial implications for patients. It also limits capacity in outpatient departments to see patients who are unwell or flaring. PIFU-LTC extends the duration of time between follow up appointments for stable patients, whilst offering the opportunity to book for review at short notice if they become more unwell. Unlike other PIFU pathways, all PIFU-LTC patients will be offered a default appointment after 1 or 2 years. This means they will not be discharged from the service if they do not contact between appointments.

• How will PIFU-LTC work in Rheumatology?

Initially we will use a model where all patients on the PIFU-LTC are offered a default, in person follow up appointment after:

- 1 year (12 months) - patient on Biologic medication e.g. anti TNF or small molecule medications e.g. “Jak inhibitors”
- 2 years (24 months) - patients on conventional DMARDs e.g. Methotrexate, those not on treatment

Prior to that, patients that have concerns about their condition can contact us via our advice line. If appropriate they will be booked directly into a clinic appointment with us.

• What number should patients call?

They should call the Rheumatology advice line on 01225 821611

• How will you decide what is appropriate for an appointment?

We do not expect that all calls will require a hospital appointment. Therefore, all calls will be screened by an administrator. They will signpost patients to other sources of information if appropriate e.g. requests for results may be directed to the medical team. If the call can be dealt with over the telephone patients may receive a call back from one of our nurse specialists. All other queries will be booked into a hospital appointment.

• After requesting an appointment, how long will it be until patients are seen?

We will aim to see patients within 10 working days weeks of their request.

• What if the patient needs a more urgent review?

We will aim to see all PIFU-LTC request appointments within 10 working days. If patients feel they need seeing sooner a telephone call with the nurse specialists will be booked to discuss this.

We are unable to offer an emergency service. Patients requiring urgent e.g. same day assessment, will be asked to contact their GP, NHS 111, local walk-in centre or, if really unwell, their local Emergency Department (A&E).

• Can I request a follow up appointment for a patient?

PIFU-LTC appointments give patients increased ownership over their follow up pathway. Therefore, requests for PIFU-LTC appointments will need to be made by the patients (or carer) themselves.

If you feel a PIFU-LTC patient needs to be seen, but they have not made this request themselves please submit a request via Cinapsis.

• How do I know if my patient is on a PIFU-LTC appointment pathway?

The decision about moving onto a PIFU-LTC is a shared one between the rheumatology service and patients. Only patients that consent to the follow up pathway will be placed on it. As such your patient should be able to tell you whether they are on the pathway. You will be informed on the clinic letter when the patient first moves onto the pathway.

Additionally, at the bottom of the clinic letter you will see the following standard text:

PIFU-LTC gives patients with long term conditions control and flexibility over their outpatient appointments. It reduces unnecessary appointments when patients are well, and improves capacity to see patients when they are struggling.
This patient is on a PIFU-LTC follow up pathway. Their default follow up appointment will take place after 1 year (for those on Biologic or small molecule medications or Biologics) or 2 years (for those on all other treatments).
To request a PIFU- LTC follow up appointment before then please call the Rheumatology advice line on 01225 821611

• What if my patient no longer wishes to be on a PIFU-LTC pathway?

We will still be offering standard follow up appointments. If they contact their consultant's secretary and let them know they wish to receive standard follow up, we will arrange this for them.

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Self-management advice

The following websites have useful information about managing symptoms between appointments which may be helpful for your patients.

Rheumatoid Arthritis

https://nras.org.uk/smile/

Ankylosing Spondylitis

https://nass.co.uk/managing-my-as/my-as-my-life/

PMR

https://pmrgca.org.uk/

Rheumatology patient podcasts

https://www.birdbath.org.uk/podcasts

References

(1) https://www.england.nhs.uk/coronavirus/documents/c0716_implementing-phase-3/#patient_follows_ups

Contact details

PIFU- LTC Telephone number: 01225 821611

Rheumatology Advice Line: 01225 821611

Rheumatology Appointment Line: 01225473401

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