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A theory of change for patient-initiated follow-up care in rheumatoid arthritis

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Abstract

Background Timely, high-quality care is critical to rheumatoid arthritis (RA) management. In Alberta, thousands of individuals with RA are waiting for care due to the resource-intensive nature of lifelong follow-ups and rheumatologist shortages. With 20–50% of routine follow-ups not leading to treatment changes or raising new concerns, many appointments may be avoidable if care were restructured. Patient-initiated models extend rheumatologist follow-up intervals beyond 12 months where appropriate, which can reduce inefficiencies and improve care access. To address provincial RA care challenges, we co-developed a theory of change (TOC) for patient-initiated follow-up care.

Methods A TOC serves to define health services interventions and their intended impact prior to implementation testing. We worked with 35 healthcare leaders, implementation experts, and patient partners to co-develop a TOC for patient-initiated RA follow-up care. During the scoping phase, we held discussions with healthcare leaders and reviewed evidence on patient-initiated follow-up models to assess their implementation potential. During the development phase, we drafted a TOC map using scoping phase findings and clinical and patient expertise. During the refinement phase, feedback was collected to optimize the TOC. Meetings were recorded, transcribed, and analyzed using deductive qualitative content analysis alongside anonymous poll results and informal feedback to guide TOC refinement.

Results The scoping phase identified challenges in RA care, including long waitlists and unnecessary appointments, which patient-initiated follow-up models have the potential to address. TOC discussions highlighted two intended impacts: (1) efficient and effective care for patients when needed, and (2) a sustainable model for RA care. Feedback in the refinement phase covered 4 topics: (1) preference for an interdisciplinary flare clinic, (2) patient selection, (3) patient education, and (4) patient monitoring. Tools and strategies were co-developed with partners to support patients (e.g., decision tool for patient-provider discussions) and the health system (e.g., monthly meetings to monitor burden). The final TOC for patient-initiated follow-up in RA details the care pathway, key resources and considerations, and evaluation outcomes.

Conclusions A patient-centered, context-specific patient-initiated RA follow-up care model was co-developed with patient and healthcare partners. An implementation pilot will test its ability to address RA care challenges.

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Keywords Rheumatoid arthritis, Rheumatology, Models of care, Access to care, Patient-initiated follow-up, Theory of change, Implementation science, Health services research

Background

Early diagnosis, targeted treatment, and regular monitoring are essential to improve long-term outcomes for individuals with rheumatoid arthritis (RA) [1, 2]. The current standard of care for rheumatology in Canada involves routine follow-up appointments every 6–12 months, irrespective of disease activity [2]. During appointments, rheumatologists assess disease activity and monitor and renew prescriptions for disease-modifying anti-rheumatic drugs (DMARDs). They also support patients with shared decision-making for available treatment options and symptom management strategies.

However, routine follow-ups may not represent the optimal approach to RA care. These frequent appointments are resource-intensive and may not be required for individuals with stable disease. Follow-up appointments account for a significant percentage of rheumatology clinic capacity, with a recent report finding that 49% of appointments did not lead to intervention or medication changes [3–5]. Since RA involves intermittent, unpredictable flare-ups, pre-scheduled rheumatology care rarely aligns with patient needs. Furthermore, RA care inefficiencies are contributing to increasingly long waitlists for initial consultation and urgent care. The median wait time to see a rheumatologist in Alberta is 84 days, double the provincial target [Alberta Health Services, internal communication]. These challenges are compounded by provincial and national rheumatologist shortages [5, 6].

New RA care models are urgently needed. In the United Kingdom (UK) and elsewhere, patient-initiated follow-up (PIFU) strategies are increasingly used to improve the efficiency and quality of care for RA and other chronic conditions [7–14]. In PIFU models, individuals with RA remain under specialty care and can access rheumatology care when needed, while regular pre-scheduled follow-ups are reduced or eliminated. A randomized controlled trial on PIFU in RA care reported a 38% reduction in rheumatologist visits over 6 years without negative impacts on pain, stiffness, or disease activity [8]. Importantly, perceptions of support and disease control were unaffected among individuals on PIFU care [9]. Given these promising findings, PIFU models are being implemented across chronic disease care in the UK [15].

To develop, implement, and evaluate complex health interventions, theory-driven approaches are recommended by the UK Medical Research Council [16]. Theory-driven approaches allow researchers to better understand intervention effectiveness and scalability, including which components have the greatest impact on clinically relevant outcomes [16, 17]. While various theory-driven approaches such as logic models have been used in implementation research, the Theory of Change (TOC) approach is gaining popularity as a flexible tool for healthcare interventions [17].

The purpose of the TOC process is to create an explicit theory for how an intervention or policy is thought to impact specific outcomes of interest [17]. It provides a structured yet adaptable approach for engaging relevant partners in intervention design and refinement prior to implementation. An emphasis on partner engagement throughout TOC development provides a comprehensive understanding of the implementation context, including available resources and potential barriers and facilitators [17]. Furthermore, a collaborative TOC approach allows relevant partners to identify and agree on intended impacts of the intervention and context-specific implementation strategies, increasing buy-in. A TOC also prompts teams to define a clear evidence-based rationale, key assumptions or conditions for implementation, and relevant outcomes that define success [17].

In preparation for implementation, we co-developed a TOC for PIFU rheumatology care in Alberta. The aim of this article is to describe the TOC process and explain how it contributed to developing a robust, in-depth, and context-specific PIFU model for RA care. The implementation of this model is being studied at an academic rheumatology site in Calgary, Alberta.

Methods

In preparation for implementation at an academic rheumatology clinic in Calgary, we co-developed a TOC for our RA PIFU model with healthcare providers (HCP) and patient partners. The study was approved by the Conjoint Health Research Ethics Board at the University of Calgary (Ethics ID: HREBA REB 22–0487, Clinical trial number: not applicable) and conducted in accordance with the Declaration of Helsinki. All participants outside the research team provided written informed consent prior to engaging in the TOC process and gave verbal consent for the audio recording of meetings.

The Calgary rheumatology and primary care context

There are 36 rheumatologists (21 at academic sites, 15 at community sites) in the Division of Rheumatology in Calgary, Alberta who provide care for adults with inflammatory rheumatic diseases [18]. The catchment area includes approximately 2.3 million individuals in southern Alberta and neighboring provinces. Rheumatology care is increasingly strained due to population growth, and specialty shortages [18, 19]. More than 3000 patients in our service area are waiting for rheumatology care [Alberta Health Services, internal communication]. In addition, provincial primary care is facing major workforce shortages, and many individuals lack a primary care physician (PCP) [20, 21].

Theory of change process

As shown in Fig. 1, we used a 3-phase approach to develop our TOC for PIFU in RA care. The scoping phase (Phase 1) focused on reviewing published literature and available resources, as well as early partner engagement. The development phase (Phase 2) led to the creation of our initial TOC map, integrating the findings from the scoping phase and clinical expertise from the core team. Lastly, the refinement phase (Phase 3) featured iterative, semi-structured group discussions with key partners to finalize the TOC in preparation for the implementation pilot study.

Theory of change co-development team

A patient- and provider-centered TOC process can increase an intervention's relevance and promote contextual tailoring of implementation strategies, contributing to a greater likelihood of success. For the present study, the term "partners" refers to all knowledge users and experts who contributed to the TOC process. This included health services and implementation science researchers, HCPs and healthcare leadership, and patients (i.e., individuals with lived experiences of RA). Key partners were recruited using purposive sampling to provide diverse perspectives across demographic backgrounds, professional roles, and RA care experiences.

HCP partners were identified through purposive sampling to ensure representation across clinics. For patient partner recruitment, posters were put up in local rheumatology clinics and emails were sent to members of the Rheum4U Precision Health Registry Platform, a web-based longitudinal cohort of patients with inflammatory arthritis [22].

Thirty-five partners participated in TOC development, including researchers, HCP (rheumatologists, clinic nursing leadership, a nurse educator, primary care providers), implementation science experts, and patients. Sixteen (45.7%) were healthcare providers, including 12 physicians, 2 nurses, 1 pharmacist, and 1 physiotherapist, all of whom had research expertise. Nine (25.7%) were researchers, including 2 implementation science experts and 6 researchers with some implementation science expertise. Of these, 9 (25.7%) held leadership positions in healthcare or academic settings. To ensure strong representation of patient voices, our team of partners included 10 (28.6%) individuals living with RA. Details on patient partner involvement across the 5 items from the GRIPP2 checklist are presented in Additional File 1 [23]. One key partner (AH), is as an individual living with arthritis who works as a knowledge broker and physiotherapist, provided input from each of these perspectives. An international expert on PIFU care from the UK provided external expertise (MP). Given the lack of physiotherapists and occupational therapists in our local rheumatology care context, these professions were underrepresented in the TOC co-development team.

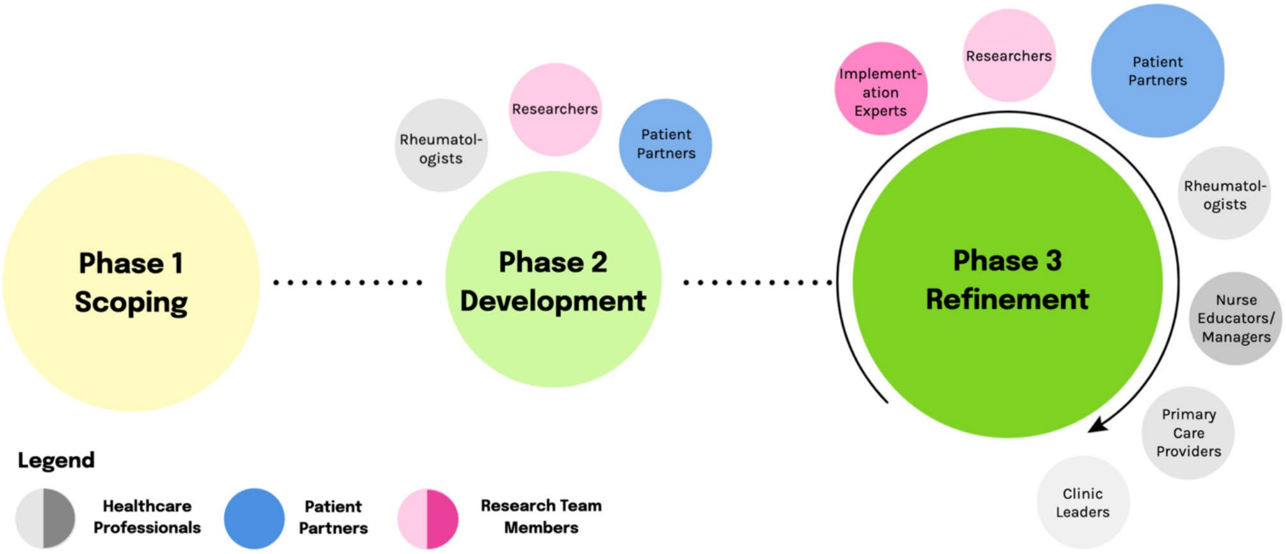

Fig. 1 The 3-phase iterative TOC development process for patient-initiated follow-up care in rheumatoid arthritis. Different shades of pink and grey represent different subgroups of the research and healthcare team. The larger blue circle in Phase 3 represents a greater number of patient partners who participated in this phase relative to Phase 2

Phase 1: the scoping phase

The first step in developing our TOC was a comprehensive scoping phase. During this phase, members of the core team held informal discussions with rheumatology leadership and clinic managers regarding potential solutions to the growing clinic waitlists and challenges to accessing rheumatology care. The core team was made up of 1 clinician scientist and 2 researchers, in close consultation with a patient partner and knowledge broker (AH) and an implementation scientist (GZ). The idea of PIFU was proposed, and the research team subsequently gathered feedback at a rheumatology division meeting. We also obtained an in-depth understanding of the local rheumatology care context via the development process for an early care pathway in RA [18]. To supplement this knowledge, a chart review was completed to understand local RA care needs [24]. This work provided an overview of current care processes, available resources for RA care, and practice variation to consider while developing a new model of follow-up care.

In addition to engaging with rheumatology care teams and leaders, we completed a scoping review of PIFU models in RA, and an environmental scan of patient resources to support RA care [25, 26]. The scoping phase thus provided a solid foundation of knowledge to draft our TOC for PIFU in RA.

Phase 2: the development phase

The second step focused on generating a first draft of our TOC. During development, we used a pragmatic approach, working with a smaller core team to draft the initial TOC map before gathering input from all partners. This approach was selected to reduce partner burden, as many partners were patients or practicing HCPs, and to shorten our timeline, given the urgent need to solve local rheumatology care challenges. The core team created a preliminary TOC map based on scoping review findings, clinical expertise, and knowledge of the local context. In line with recommendations, development began with agreeing on the intended impact of the intervention and working backwards to identify potential causal pathways and available resources to achieve this impact [17]. After the core team meetings, the drafted TOC map was presented to partners for feedback.

Phase 3: the refinement phase

For phase 3, a collaborative, iterative co-design process was used to gather partner feedback and refine the TOC. A half-day, hybrid (i.e., in-person and virtual attendance) TOC workshop was held to gather input from HCPs and research team members, including our lead patient partner and knowledge broker (AH). The drafted TOC map from phase 2 was presented, followed by a series of discussions to actively refine the TOC. To encourage participation, a series of prompts were discussed via anonymous polling (Poll Everywhere), the Zoom chat function, and real-time conversation. Of the 35 partners, 19 attended this workshop. For those who were unable to attend, four additional virtual meetings were held to gather feedback. All partners attended at least 1 meeting.

Given the societal and implied power imbalances between patient partners, HCPs, and researchers that can limit the depth of patient feedback in research, two separate TOC workshops were completed with patient partners only. These workshops followed the same format as above and were intended to ensure a safe space for patients to comment openly on the model of care. All 10 patient partners attended at least one of these workshops.

Feedback collected via the three TOC workshops was used to refine the initial TOC in preparation for an implementation pilot study. During the later stages of model refinement, partners with direct roles in the implementation of our PIFU model (e.g., site leads, nursing staff, division pharmacist, clinic administrators) were prompted for additional feedback. This was accomplished by sharing the TOC findings and implementation plan for feedback via email, at leadership meetings, and during a formal presentation to all nursing and administrative staff.

Data collection and analysis

TOC workshop recordings, poll results, and Zoom chat histories were saved with consent at the end of each meeting. Feedback was also collected through email communication and comments on TOC draft documents shared with partners. TOC workshop recordings were transcribed verbatim using a professional transcription service. Research team members analyzed the transcripts in NVivo 12 with a pragmatist lens using deductive qualitative content analysis to identify critical feedback, thereby informing refinement of the TOC map and implementation plans [27, 28]. Conflicts were resolved via discussion between researchers (CB, KW, KD, SZ).

Results

Current state of care

Completion of the scoping phase provided a comprehensive understanding of how PIFU has been successfully implemented in RA care, the current state of rheumatology care in Alberta, and available resources to support disease self-management between visits [24–26]. These findings informed the adaptation of existing PIFU models to our care context. They also emphasized the need to develop tailored self-management and patient education resources for implementation. Furthermore, prior work in Alberta highlighted three RA care challenges to address: mismatches between patient needs and appointment scheduling, unmet benchmarks for appointment wait times, and limited workforce capacity due to rheumatologist shortages [19, 29, 30]. To build upon this knowledge, the TOC development phase for our PIFU model started by discussing its intended impact on rheumatology care.

Table 1 Themes from preliminary TOC discussions to decide on desired outcomes for the future model of rheumatology care

Theme	Description
Desired outcomes	
Theme 1: Efficient and effective care delivered to patients when they needed it	Patients seen when they need to be seen *“I’ve had so many appointments where my specialist just wanted to talk about sports and other things [they] enjoyed talking about. [They] didn’t need me there, so I would have been using up clinical resources unnecessarily.” (Patient 8)*
	Maintaining low disease activity between visits *“I could think everything is fine, and things could not be fine. Just because I think we do, for me personally, I mean, you tolerate a lot. What is an acceptable baseline? And then you inch off of that baseline that was acceptable and deteriorate a little bit, and your life is busy, and you’re working really hard, and you”ve got all these priorities. It is very, I know for myself, I would be the last priority for saying to myself: I need to have a follow-up. I know that.” (Patient 1)*
	Safeguards built into new care delivery *“To me, in a perfect world, if you want to do this, you get somebody else that’s working with this doctor. They’re both on your case.” (Patient 6)*
	Clear communication on how to access care *“One of the issues that I’ve had [is] communication with my rheumatologist. [It] has been difficult. If I wanted to pick up the phone and call her, it’s a Herculean effort. It’s almost like they’re hiding [in] the rheumatology clinic sometimes. Phone numbers seem to change. If there were a text option for communication with someone in that office, I think that would be useful for me.” (Patient 2)*
	Patient needs met via education *“[We need] opportunities for education” (Patient 9)* *“How do we find out about new medications that may be better for us?” (Patient 8)*
	Patient preferences for care considered *“The doctor I had before, it’s like, shut up, sit down, I’m in charge. I’m the expert. I will tell you what to do. So respect [of my preferences] is crucial.” (Patient 6)*
Theme 2: An improved model of rheumatology care for providers and clinics	Increased capacity and access *“Having increased capacity for future patients, with potential reduced wait times” (HCP 7)*
	Sustainable and scalable *“The system for re-accessing care is not causing an overburden on clinic staff and on physicians” (HCP 6)* *“I would add scalable. That way, it’s not just our clinic, but smaller groups or bigger groups could implement whatever you come up with as well. (HCP 1)”*
	Physician satisfaction *“I think we would all want a highly functioning clinic where we are having a collegial environment where people are communicating not just with the patients, clearly, but with each other” (HCP 19)*
	Patients empowered to be active partners in their care *“We have limited resources of highly qualified professionals, and you want to just use those to your best capacity, so the clinics are always thinking about how the patients join in their care, how are they super engaged, knowledgeable, up to date about what to do next, what can they expect about the service they are going to get.” (HCP 12)*

Desired outcomes for a future state of care

Key themes from these discussions for improving rheumatology care, as well as sub-themes and representative quotes are presented in Table 1. Theme one emphasized the need to provide efficient and effective care to patients when needed. A patient-centered model that considers patient care preferences, provides sufficient patient education, and ensures that appointment timing matches patient needs was desired. Furthermore, processes to maintain care quality were seen as crucial. This included maintaining low disease activity between lower frequency visits, safeguards to provide timely urgent care between visits, clear communication on how to access care, and clear outcome tracking processes. Theme two centered around creating an improved model of rheumatology care for providers and clinics. Factors thought to contribute to improved care were increasing capacity and timely access, a sustainable and scalable implementation plan, reduced physician burnout and improved job satisfaction, and empowering patients to be an active part of their care.

Initial intervention description

The initial TOC diagram created during the development phase is shown in Fig. 2. Model inputs, interventions, intermediate outcomes, assumptions, long-term outcomes, and impacts are color coded. Indicators for evaluating the success of the new model were not discussed until the refinement phase.

Key inputs included the realities of the local context, with high follow-up demands for stable RA patients and limited ability of primary care to provide support due to high strain, as well as essential resources needed to support a PIFU model. Prior to enrollment in the model, careful patient selection, sufficient patient education, and clear baseline documentation were hypothesized as necessary pre-conditions to a successful and safe use of the PIFU care model. Once enrolled, the core team envisioned a care model with an annual virtual rheumatology visit with an alternate provider (e.g., pharmacist, to meet requirements for medication renewal), an interdisciplinary triage process for flares and acute management, and urgent rheumatologist re-evaluation as needed to handle urgent concerns (e.g. flares, increased disease activity) between visits. Significant discussion occurred during this phase regarding the potential involvement of PCPs and concerns due to the current primary care burden in the province.

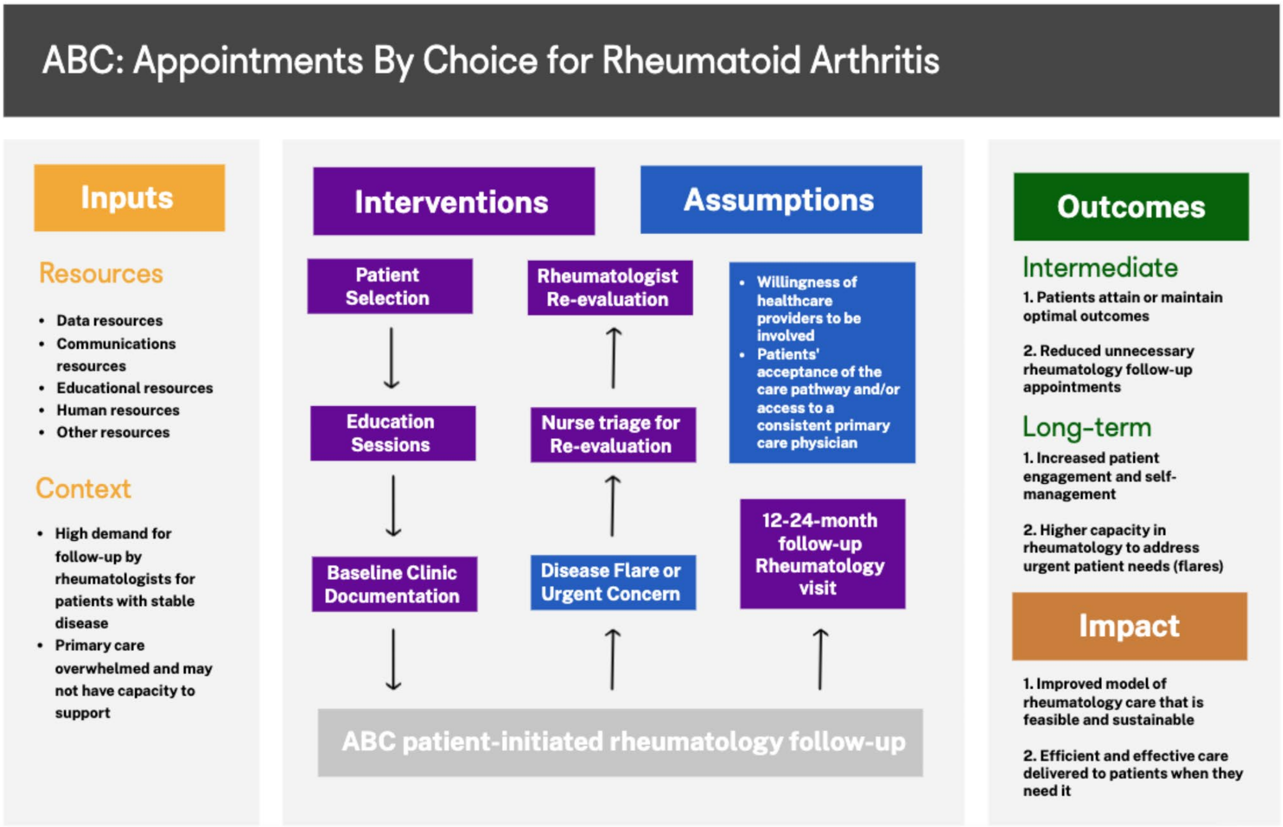

Fig. 2 Initial TOC map after the development phase

Key areas of discussion during TOC refinement

Partner feedback during the refinement phase centered around four key topics: (1) choosing between an interdisciplinary flare clinic or a shared care model with primary care, (2) patient selection, (3) patient education, and (4) patient and implementation monitoring.

Choosing between patient-initiated follow-up supported by an interdisciplinary flare clinic or a shared care model with primary care

A challenging decision during the TOC refinement phase was to opt against using a shared care model where ongoing rheumatology care is transferred to PCPs, which is commonly described. Instead, partners agreed on a PIFU approach supported by an interdisciplinary flare clinic model. For patients on conventional synthetic DMARDs (csDMARDs), PCPs may feasibly manage care as they can prescribe csDMARDs and order lab tests to monitor the patient, requesting specialty care when needed. However, advanced therapies (i.e., biologics and targeted synthetic therapies) can only be prescribed by a rheumatologist and require a specialist visit every 12–24 months. HCPs voiced concerns about primary care burden:

> *I've been increasingly worried about the workload of primary care and of many of my patients who are losing primary care physicians. So I think the model needs to be designed such that the primary care team is aware that this is happening, and how to access things if the wheels go off. But that, our team would be ordering the labs, and technically the primary contact for things like a flare … So it would be more like a virtual follow up still within the clinic. (HCP 20).*

Patient partners were also reluctant to have PCPs responsible for their rheumatology care. They noted that PCPs may lack experience with RA drug selection, drug interactions, and RA care complexity to provide high quality rheumatology care.

> *I hope that it doesn't lead to more of the function of the rheumatologist being passed to the family physicians, because often the family physicians are not familiar with the interaction of the drugs and the condition (Patient 4).*

Among PCPs participating in the TOC workshops, opinions were divided. Some argued that PCPs should have the skillset and capacity to take on a shared care model, whereas others felt an interdisciplinary flare clinic model to be more appropriate due to primary care strain. To promote effective care coordination between rheumatology and primary care, the team decided to draft and pilot a letter for primary care teams that will inform them of patient participation in the follow-up model and clarify that the patient is not being discharged from rheumatology.

In the UK, some PIFU strategies reserve a percentage of available clinic appointments (e.g., 5 slots per 100 patients) for PIFU care [8, 10]. This was considered infeasible due to rheumatologist workloads, with no capacity to free up appointments at the proposed pilot clinics in Alberta. An interdisciplinary flare clinic model was ultimately seen as preferable for the local context. In this model, an experienced rheumatology nurse or pharmacist acts as the first line of contact for patients, managing medications and supporting day-to-day concerns remotely. As needed for urgent concerns, the nurse or pharmacist triages patients for rheumatologist follow-up. However, HCPs voiced concerns about clear roles and responsibilities, patient monitoring, capacity limitations, and required skills training to manage this additional flare clinic. For the implementation pilot, a pharmacist-led clinic is being piloted due to the availability of a rheumatology pharmacist with extensive training and sufficient capacity. Nurse-led models are also being considered to enhance future scalability. Solutions will be required to address barriers to nursing involvement, which include nurse shortages, lack of capacity, inability to prescribe medications, high staff turnover, and less specialized rheumatology training.

> *Maybe one of our barriers to getting the nurses involved is where does that [current patient care] workload shift to (HCP 3).*

When presented with options that included patient self-monitoring via questionnaires and telephone triage, many patient partners expressed a preference for accessing the interdisciplinary flare clinic via telephone. HCPs also spoke to patient capability to self-identify a flare and their ability to call the clinic when needed.

> *I would like to have the opportunity to call directly when I'm flaring, because again, it's interactive, questions and answers (Patient 6).*
>
> *Patients self-identify when they're flaring. They call repeatedly and they call early and they call often when they're in pain, most of them (HCP 1).*

TOC participants agreed that having multiple options available to patients (i.e., including optional flare score questionnaires to fill out) would best meet diverse patient needs and preferences.

Patient selection

Selection criteria for identifying suitable patients for a PIFU model were carefully considered. Whereas some prior trials of PIFU models included consecutive patients or only patients on csDMARDs, our discussions identified various patient factors that may impact appropriateness of this care model for individuals. Factors included disease duration, disease stability (i.e., no recent changes in disease activity or medication), and other health concerns. Partners also emphasized the importance of patient and caregiver understanding of the disease and treatments, knowing when to access care, and access to care. Potential challenges for individuals with language barriers, or those struggling with the transition from pediatric to adult care, were noted. HCPs agreed that patient preferences and comfort with this model may differ due to variation across these factors. They raised concerns about signing up patients who are not suited for a patient-initiated pathway due to care complexity. One HCP noted:

> *I think those [more complex] people are going to self-select out of this [due to concerns]. I think some of that care complexity is going to take care of itself. (HCP 1).*

Another concern was that some patients may not be comfortable re-initiating care when needed, which is reflected in the following HCP quote.

> *Patients who don't want to be perceived as a burden (may not re-initiate care) (HCP 9).*

Lastly, HCPs recognized the risk of their decisions biasing patient access to care and the need to be cautious with decision-making to "do no harm".

> *Essentially if you're selecting people then you are passing a judgment on all sorts of different things … their health literacy and cognitive status and function and all of that. At the same time, you could be a bit more stringent in terms of when you would make it available to everybody versus when you make it available to some people, … let's say somebody [who] is very in tune [with their disease] (HCP 11).*
>
> *I think initially, maybe we play it safe and offer this to a more restricted group of patients … where we have the least concern that things might fall through the cracks. (HCP 8).*

These extensive discussions around patient selection emphasized the importance of shared decision making when deciding if PIFU is right for an individual. Patient partners voiced concerns about the lack of shared decisions in prior care, where their voices were muted rather than amplified.

> *The doctor I had before, it's like, shut up, sit down, I'm in charge. I'm the expert. I will tell you what to do. Especially when you're a woman, that does not go very well because we deal with that all the time. So respectful care is crucial. (Patient 6).*

A shared decision tool was therefore co-developed with patient partners to guide decision-making, which is being piloted in our ongoing implementation pilot.

Patient education

Patient education was identified as a key component in the scoping phase, and its importance was re-emphasized throughout discussions with our key partners. Options considered for delivering education included print materials, virtual group sessions, in-person group sessions, 1–1 sessions, websites, and video content. During TOC workshops, patients and providers debated the best format for patient education, agreeing that a mix of delivery methods would be ideal to suit a wide variety of age groups and preferences.

> *To truly be patient-centered, all options should be available (HCP 10).*

To prioritize patient preferences, we polled patient partners during the TOC workshop, with the top three preferred delivery methods being written materials, virtual group sessions, and a website.

In direct response to input from the TOC workshops, three patient education materials were co-developed with members of the TOC team, additional patient partners, and knowledge translation as well as design experts. The first is a discussion tool to guide shared decision making about moving to a PIFU pathway. The second is an information sheet to answer frequently asked questions about the pathway. The third is a flare action plan that provides practical advice on how to self-manage flares and when to contact the interdisciplinary flare clinic. All materials will be available as print and digital versions, either directly in-clinic or at a study-specific website. They are currently being piloted and refined through our implementation pilot study. Virtual education sessions were not developed for the initial pilot due to HCP concerns about poor attendance at previous education sessions despite a resource-intensive planning process.

Patient and implementation monitoring

Comprehensive monitoring of patient and implementation outcomes was identified as a crucial component of the model. Partners agreed that monitoring relevant outcomes would be important to understand the implications of implementing the PIFU model. Consistent baseline data collection (e.g., standard medical information, patient activation measure) for all patients was seen as necessary to maintain high quality follow-up care.

> *I'm thinking about 'what is the purpose of the baseline documentation?' and 'what are the right measures to put in there?' And one purpose that I see is making sure that there's no unintended consequences of this new model. What we need to track at baseline and afterwards to make sure that we haven't had any unintended consequences. The mental health, the anxiety, the depression, obviously the patient reported outcome on the symptoms to make sure that over time they haven't worsened while in this new model. [We can] use that as a way to know is, is this model appropriate for this patient or not? (HCP 8).*

Furthermore, partners emphasized that data collection between appointments would improve patient monitoring and guide decisions on patient re-entry into usual care. Patients and providers debated whether self-report questionnaires should be used at regular intervals, or if a simpler "call when you need" approach would be sufficient for patients. Due to the mixed perspectives in this regard, an optional quarterly validated self-report flare questionnaire (i.e. the Rheumatoid Arthritis Flare Questionnaire [31]) will be tested during the implementation pilot. Responses will be monitored by the interdisciplinary flare clinic, with phone or in-person follow-ups scheduled as needed.

> *I think we have learned some things through COVID, in terms of [...] self-assessment [questionnaires]. I think the public is more used to answering a couple of simple questions. First, hopefully with a validated tool to indicate flare in order to help direct resources appropriately. (HCP 21).*

> *The thing about completing the [flare] tool every three months for me is it makes me prioritize myself. And so, it's a reminder. Remember, you need to be thinking about these things, and just taking a few minutes to check in with yourself. (Patient 1).*

> *I think when you're having a flare, you are in pain, you don't need any extra steps. (Patient 6).*

With regards to the data collection process, conversations focused on the importance of considering both the value of the data while minimizing the added data entry burden for patients and providers.

> *If we're thinking about adding extra tools for people to complete … given that it's not currently part of any kind of standard of care right now, that may [decrease] the feasibility. (HCP 9).*

This balance was perceived as important both for the pilot study and long-term pathway implementation.

Table 2 Unintended consequences of the patient-initiated follow-up model from the TOC workshops

Theme	Quotes
Patient-related consequences	
Losing patients to follow-up	*"Patients feel overburdened and abandon follow up"* (HCP 10)
	"How do we track patients who are not doing labs" (HCP 6)
Not tapering medications	*"Patients who are stable remaining on meds and not having meds tapered when appropriate"* (HCP 7)
Changing physician and patient relationships	*"Less comfortable with rheumatologist if no regular appointment"* (HCP 9)
	"I hope that it doesn't lead to more of the function of the rheumatologist being passed to the family physicians, because often the family physicians are not familiar with the interaction of the drugs and the condition" (Patient 4)
Inequities	*"Increasing inequities"* (HCP 15)
Patient confusion	*"Patient might get confused about if they're still a patient of our clinic"* (HCP 13)
Health system consequences	
Administrative and nursing staff burden	*"Consider roles of administrative staff in clinic and in booking offices"* (HCP 12)
	"So one of it might be overburdening the nursing staff" (HCP 3)
Rheumatologist burden and job satisfaction	*"And if the rheumatologists are seeing only flaring patients, and sick of the sickest of the sick, we have to take that into consideration. Because that's not what we're used to. We have sort of half emergencies, half stable follow ups, and people having … So that could change the workflow and how people are feeling about their jobs"* (HCP 13)
	"We have doctors, they probably have appointments scheduled back to back to back all day, and suddenly we add this [virtual follow-up care] that they have to address and deal with. When are they doing that? And are we going to be, as a result of that, they have to cut back on seeing you in person? So that is a concern of mine." (Patient 6)
Overburdening PCPs with a shared care model	*"And the other unintended consequence [of sharing patient-initiated follow-up with primary care] is overburdening primary care … I think we are all starting to feel a bit of a pinch for sure."* (HCP 5)

Unintended consequences and mitigation strategies

Feedback from core team members and key partners throughout TOC development led to the identification of potential unintended consequences for the proposed PIFU model with respect to patients as well as the healthcare system (Table 2). For patients, if the model was not carefully implemented it could lead to greater unmet healthcare needs and contribute to worse patient outcomes (e.g., undetected active disease, poorly managed flares). For healthcare systems, the model could contribute to additional burden and ultimately burnout among already strained healthcare teams.

Mitigation strategies were thus embedded into the model to minimize its potential negative impact. Using the decision tool, patients will be encouraged to discuss PIFU participation with their rheumatologist and make an informed decision. Shared decision-making will ensure that suitable patients are enrolled in the pathway and strengthen the physician-patient relationship by respecting preferences and optimizing buy-in. Furthermore, patients will be able to return to usual care at any time. A flare clinic phone hotline, pharmacist monitoring of labs, and completion of an optional quarterly flare self-check-in will allow for continued high-quality care. To monitor potential healthcare system consequences, consistent feedback from healthcare staff regarding burden and job satisfaction will be captured through regular plan-do-study-act meetings and qualitative interviews.

Final model for patient-initiated follow-up in rheumatoid arthritis

After multiple rounds of iteration and refinement, the PIFU model was finalized. Based on feedback from patient partners, our care pathway was named the "Appointments By Choice" (ABC) pathway. A pathway diagram was created, as shown in Fig. 3. The final model integrated formal feedback from the TOC workshops and additional meetings, as well as informal feedback obtained via email communication and in-person discussions with key partners before and after the workshops.

At baseline, eligible patients (i.e. no major flares or medication changes within 6 months, no major comorbidities or unaddressed medical concerns, demonstrated confidence to notice flares and contact the clinic if persistent) will be prompted to make a shared decision with their rheumatologist about moving to the ABC pathway and adjusting their follow-up visit frequency. Patients will be able to extend the follow-up interval with their rheumatologist from 6 to 12 months to 12–24 months or longer if appropriate. If necessary for medication renewal, patients who agree to a follow-up interval beyond 12-months will receive a pharmacist phone call at 12 months to review labs and complete any other renewal requirements. Upon moving to the ABC pathway,

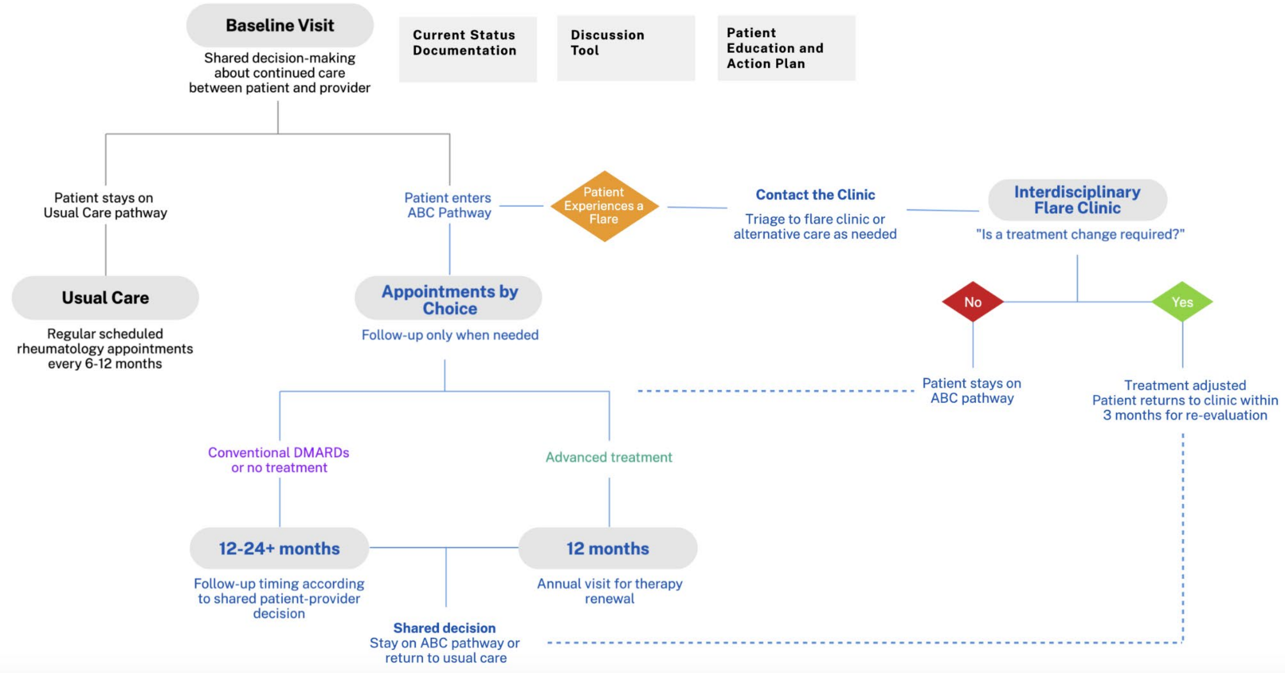

Fig. 3 Flow diagram for the updated ABC patient-initiated follow-up pathway

patients will be provided with education materials to help them self-manage flare-ups and instructed to contact the interdisciplinary flare clinic for triage as needed. An optional self-report flare questionnaire may be completed every 3 months, or more frequently if desired. At each follow-up visit, a shared patient-provider decision will be made to stay on the PIFU pathway or return to usual care.

This model is currently being tested in an implementation pilot study at a local rheumatology clinic. Evaluation indicators and associated measures for the model, which were chosen based on feedback obtained during the TOC process, are outlined in Additional File 2. The outcomes of this study will be used for additional model refinement in preparation for provincial implementation.

Discussion

Our current model of RA specialty care, which includes lifelong follow-up every 6–12 months, is overburdening the healthcare system and failing to meet patient needs. There are growing patient waitlists and increasing difficulties accessing urgent rheumatology care provincially. In this article, we described the development of a new ABC model for RA care. This model was co-developed with HCPs, patient partners, and additional experts to overcome existing challenges and improve the quality of care. Using a structured TOC approach prompted careful consideration of existing evidence and anticipated risks, leading to iterative refinements of the model. Furthermore, meaningful input from diverse partners contributed to well-defined impact goals, risk mitigation strategies, and outcome measures.

There are important benefits of developing a TOC for interventions prior to implementing them in complex healthcare contexts. The process has value for anticipating and proactively addressing implementation challenges. For example, discussing our intended impact with healthcare teams during the scoping phase increased buy-in to change. This phase also increases awareness of barriers to successful implementation, as discussed by Bamford et al. and echoed during our study [32]. Two notable barriers highlighted during our scoping phase were rheumatologist shortages and the lack of quality patient education materials for RA self-management. In-depth discussions during the refinement phase prompted additional tailoring of the PIFU model to the contextual realities of our implementation sites. For example, a novel pharmacist-led interdisciplinary flare clinic approach was favored over previous PIFU models featuring nurse- or primary care-led approaches [25]. An iterative refinement process can thus address the lack of fit between an intervention and the implementation context, a common pitfall in failed implementation projects [33]. Lastly, partner feedback on relevant outcomes during TOC workshops may lead to a more rigorous and meaningful evaluation of the intervention. Capturing metrics that matter to key partners is essential to sustained implementation.

The TOC development was not without its challenges. A major hurdle was the ever-increasing strain on our provincial healthcare system. The effect of HCP shortages and staff burnout following the COVID-19 pandemic seemed to have a negative impact on overall healthcare partner engagement throughout the TOC process. Furthermore, patient engagement in research as well as patient trust in health institutions has been negatively impacted by the pandemic [34, 35]. To improve engagement from patient and healthcare partners, we offered 1–1 meetings and flexible schedules for discussion. An additional challenge that arose during the refinement phase was the differences between implementation contexts (e.g., staff capacity, funding availability, access to allied health professionals and nursing staff) at academic compared to community sites [36]. These contextual complexities made it difficult to propose a single model of care. Ultimately, a starting model was developed that can be adapted over time during spread and scale. Future iterations may integrate successful approaches from other provinces (e.g., increased nursing involvement, additional patient education, improved funding models for interdisciplinary care) [37].

Compared to previously reported TOC processes, our 3-phase approach was slightly more streamlined [32, 38, 39]. The process was adapted based on the understanding of our local context and the target timelines for implementation. For example, given pandemic-induced strain on healthcare teams and patients, the core team decided to engage key partners only during the later refinement phase to reduce participant burden. However, the overall process for developing a TOC remains similar throughout the literature. The value of iterative refinement and meaningful partner engagement has been consistently emphasized. A broad range of data sources should be integrated into the process, including published literature, practice-based evidence, partner experiences and perspectives, and contextual factors at implementation sites. Notably, we also recognized the value of informal discussions that took place outside of the structured TOC workshops and interviews. For example, clinicians on the research team gathered meaningful feedback from healthcare teams in the rheumatology clinic during staff meetings and 1:1 conversation with clinic leaders. The combination of formal and informal feedback added a valuable layer of depth to the present study.

Strengths of the present study include the extensive scoping phase and enhanced patient partner engagement due to patient-researcher ratios of at least 1:1. Conversely, certain limitations should be acknowledged. While we purposively recruited a diverse group of partners, some groups may have remained underrepresented (e.g. non-English speakers, rural populations, ethnic minorities). By implementing this model, we strive to improve overall health equity in care delivery by allowing patients with stable disease and a good understanding of their RA to access care when needed, thereby freeing up rheumatology clinic capacity for patients with higher healthcare needs and complexity. Our patient partners were well-informed and had stable disease, suggesting that their feedback was representative of this target population. Notably, potential language barriers to PIFU models remain important to understand and address through future research.

Conclusions

The 3-phase TOC co-development process represented a valuable first step towards addressing rheumatology care challenges in Alberta. Following a comprehensive review of published evidence and the local context, a patient-initiated follow up model was co-developed and refined. Discussions with key partners led to the identification of impact goals, implementation needs and assumptions, risks, and relevant outcomes. These results shaped subsequent implementation and evaluation planning, including the selection of implementation strategies and evaluation metrics for our PIFU model. An implementation pilot study is now underway. Findings from this pilot will inform further model optimization in preparation for province-wide implementation.

Abbreviations

ABC	Appointments by choice
csDMARD	Conventional synthetic disease-modifying anti-rheumatic drug
DMARD	Disease-modifying anti-rheumatic drug
HCP	Healthcare provider/providers
PCP	Primary care provider
PIFU	Patient-initiated follow-up
RA	Rheumatoid arthritis
TOC	Theory of change
UK	United Kingdom

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s41927-025-00481-3.

Supplementary Material 1

Supplementary Material 2

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Author contributions

ME: Methodology, Writing – Original Draft, Writing – Review & Editing. KW: Methodology, Writing – Original Draft, Writing – Review & Editing, Project Administration. KD: Writing – Review & Editing, Project Administration, Funding Acquisition. SZ: Methodology, Writing – Review & Editing, Project Administration. SS: Conceptualization, Writing – Review & Editing, Funding Acquisition. GLZ: Conceptualization, Writing – Review & Editing, Funding Acquisition. AMH: Conceptualization, Writing – Review & Editing, Funding Acquisition. SLM: Conceptualization, Writing – Review & Editing, Funding Acquisition. GH: Conceptualization, Writing – Review & Editing, Funding

Acquisition. DL: Conceptualization, Writing – Review & Editing, Funding Acquisition. MRWB: Conceptualization, Writing – Review & Editing, Funding Acquisition. NP: Conceptualization, Writing – Review & Editing, Funding Acquisition. MJ: Conceptualization, Writing – Review & Editing, Funding Acquisition. MP: Conceptualization, Writing – Review & Editing, Funding Acquisition. MT: Conceptualization, Writing – Review & Editing, Funding Acquisition. KLT: Conceptualization, Writing – Review & Editing, Funding Acquisition. AC: Conceptualization, Writing – Review & Editing, Funding Acquisition. CEHB: Conceptualization, Methodology, Writing - Original Draft, Writing - Review & Editing, Supervision, Project administration, Funding acquisition.

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Data availability
The data used for the current study is available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Ethics approval was obtained via the University of Calgary Conjoint Health Research Ethics Board (REB22-0487). All participants outside the research team provided written inform consent prior to engaging in the theory of change process and gave verbal consent for the audio recording of meetings. Clinical trial number: Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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