

AD-Profile

Designing and Building a Patient-Profiling Questionnaire for Anti-Amyloid Treatment Discussions in Early Alzheimer's Disease

Summer Research Report

May 1 - August 31, 2026

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Executive Summary

This report documents a four-month undergraduate summer research studentship (May 1 - August 31, 2026) in the Interactions Lab and HealthVis Futures Lab at the University of Calgary, supervised by Dr. Fateme Rajabiyazdi. The project produced **AD-Profile**, a web-based patient-profiling questionnaire for people living with early Alzheimer's disease and their care partners. AD-Profile collects personal and practical information that clinical records rarely capture; such as preferences, values, concerns, caregiver support, costs, travel constraints, and daily-life circumstances. It then presents it to clinicians as a clear, structured summary before an appointment about anti-amyloid treatment options such as lecanemab and donanemab.

The summer's work progressed through four phases. First, a full ethics application was researched and written for the University of Calgary Conjoint Faculties Research Ethics Board (REB26-0844), covering study rationale, a clinician co-design protocol, recruitment, consent, and data-privacy planning (May 1 - June 15). Second, a structured literature review of 11 peer-reviewed papers was completed, extracting **196 evidence quotes** and coding them into a **14-concept taxonomy** of decision-relevant patient information (June 15 - July 14). Third, the taxonomy was translated into a bank of **80 candidate questionnaire items**, each traceable to specific literature evidence, and shortlisted with the research team to a final set of **20 questions** (July 14 - July 29). Fourth, the questionnaire was designed as 20 interface mockups and then implemented end-to-end as a production web application; patient and clinician portals, accessibility features (voice narration and a color-blind mode), CSV export/import, a moderated patient-clinician chat, and a cloud Postgres database - deployed publicly on Vercel (August 1 - 11).

The planned clinician co-design sessions could not be held within the short studentship window; they are scheduled to continue under the supervising professor during the 2026-27 academic year, using the ethics protocol, question bank, and working prototype produced this summer as their foundation. The report closes with reflections on the research experience, the challenges encountered (both methodological and technical), the limitations of the current prototype, and the roadmap for the project's next stages.

1. Introduction

1.1 Background and Motivation

Alzheimer's disease care is at an inflection point. Two anti-amyloid monoclonal antibody therapies, **lecanemab** and **donanemab**, have moved from clinical trials into real-world practice. They are the first treatments that act on a fundamental disease mechanism, amyloid-beta deposition, rather than only managing symptoms (Smith et al., 2025). Lecanemab was approved for use in Canada effective January 2026, although public reimbursement was not recommended and coverage differs across jurisdictions (Weiss et al., 2026). These drugs are not a cure. In trials, lecanemab slowed clinical decline by roughly 27% over 18 months - approximately four to five months of delayed progression - and donanemab by 35% in participants at an earlier disease stage (Frank et al., 2024). Whether that modest, population-average benefit is meaningful for an individual patient remains actively debated (Smith et al., 2025).

What is not debated is the burden the treatment places on patients and families. Eligibility requires confirmation of amyloid pathology by PET imaging or lumbar puncture, together with APOE genotyping, coordinated through specialist memory clinics (Weiss et al., 2026). Treatment means intravenous infusions every two weeks (lecanemab) or every four weeks (donanemab) for 18 months or longer, repeated safety MRI scans to monitor for amyloid-related imaging abnormalities (ARIA); which occur in up to 37% of treated individuals and are symptomatic in 3-6% - plus travel, waiting, potential out-of-pocket costs, and significant caregiver involvement (Frank et al., 2024).

The decision to pursue this pathway is therefore deeply personal. Real-world studies show that patient preference and practical circumstances, not just medical eligibility, dominate outcomes: in a US Veterans Affairs cohort, only 5.3% of reviewed patients reached candidacy or treatment, with "lack of patient interest or resource constraints" among the most commonly documented reasons for exclusion (Mittler et al., 2025); at a Colorado specialty clinic, 37.4% of patients who completed intake ultimately declined therapy (Carlisle et al., 2026). Yet the information that shapes these decisions, a patient's travel plans, tolerance of risk and uncertainty, caregiver availability, financial situation, daily routines, and personal goals; is precisely the information that clinical records usually do not contain. Clinicians must spend scarce appointment time gathering it from scratch before a genuine, shared decision can even begin.

AD-Profile addresses this gap. It is a web-based questionnaire that patients and care partners complete before an appointment, capturing preferences, values, concerns, and practical constraints, and presenting them to the clinician as a structured, flagged summary. It deliberately does **not** recommend treatments, judge eligibility, or weigh options, it profiles the patient so that the clinical conversation starts from what matters to them.

1.2 Research Question and Objectives

The project's guiding research question, as stated in the ethics application, is: **"How can a tool collect information from patients and caregivers, and then present it to clinicians, to support more efficient and patient-centred decision-making for anti-amyloid treatment options in early Alzheimer's disease?"**

The objectives are to:

- Co-design a tool that captures patient and caregiver preferences, values, concerns, and practical constraints not usually found in medical records; and
- Design the tool to present this information to clinicians in a clear and useful way.

Within the summer studentship, my responsibilities covered the groundwork for both objectives: writing the ethics application, conducting the literature review, developing and shortlisting the questionnaire content, and designing and building the working web platform that future co-design sessions will iterate on.

1.3 A Note on Naming: From AD-Decide to AD-Profile

The tool was developed through most of the summer under the working name **AD-Decide**. In August, following review with my supervisor, it was renamed **AD-Profile**. The working name implied a decision aid whereas this tool does not present options, assess eligibility, or advise. It collects and structures patient-provided context, a **patient profile**, for the clinician to use in conversation. The new name describes the tool's actual function accurately, avoids overstating its clinical role, and prevents misunderstanding by patients, clinicians, and ethics reviewers. All code, documentation, and user-facing text were updated to the new name on August 6, 2026.

1.4 Report Structure

Section 2 reviews the literature that grounds the project. Section 3 describes the methods of each project phase, including the planned co-design methodology. Section 4 presents the results: the ethics application, the literature-review corpus, the question bank, and the built platform. Section 5 discusses achievements against the original plan, what was not possible, challenges, personal reflections, limitations, and future work. Section 6 concludes. Appendices A-D contain the full 20-question instrument, the concept taxonomy, the 80-question bank, and a technical inventory of the platform.

2. Related Works

Eleven peer-reviewed papers were reviewed in depth (Section 3.3 describes the method). They fall into four themes: the clinical evidence and Canadian context for anti-amyloid therapy; real-world implementation and the patient journey; decision support and knowledge translation in dementia; and design methods for health communication tools.

2.1 Anti-Amyloid Therapies and the Canadian Context

Frank et al. (2024) provide the foundational primer for Canadian family physicians: lecanemab demonstrated a 27% slowing of clinical progression over 18 months (about 4-5 months of delay) and donanemab 35% among participants with low-to-medium tau pathology; treatment requires biweekly or monthly one-hour infusions for typically 18 months, biomarker confirmation via amyloid-PET or CSF analysis available only through specialized memory clinics, baseline and repeated safety MRIs for ARIA monitoring, and, in the United States, costs of US\$26,500 per year. Crucially for our project, they emphasize that suitable candidates are “motivated patients... willing to undergo extensive investigations and treatment,” making patient willingness itself a clinical variable.

Smith et al. (2025), writing for the Canadian Consortium on Neurodegeneration in Aging, reviewed the trial evidence and its system implications for Canada. They found high-quality evidence of statistically significant group differences but “mixed views on the clinical relevance of the observed differences and the value of therapy for individual patients.” Their consultations with people with lived experience surfaced themes of patient and care partner choice, quality of life, access to varied care options, and resource constraints, and concluded that treatment decisions are personal, depending on life stage, disease stage, caregiver support, service accessibility, and ability to pay. This paper contributed the largest share of patient- and caregiver-sourced evidence to our question bank.

Weiss et al. (2026) describe the state of lecanemab in Canada after its January 2026 approval: eligibility determined by specialists using APOE genotyping and CSF or PET confirmation, negative reimbursement recommendations from Canada’s Drug Agency and Quebec’s INESSS, jurisdictionally uneven coverage, and an explicit call for shared decision-making between providers, patients, and caregivers, exactly the conversation AD-Profile is designed to prepare.

2.2 Real-World Implementation and the Patient Journey

Four papers document what actually happens when these therapies meet real clinics and real patients. Mittler et al. (2025) manually reviewed 55,000 clinical notes for 1,064 US veterans whose records mentioned lecanemab: only 5.3% reached the point of being a candidate, scheduled, or infused, and “lack of patient interest/resource constraints” was documented far more often among excluded patients (24.6%) than included ones (3.6%). Carlisle et al. (2026) report similar patterns from the University of Colorado’s anti-amyloid therapy clinic, where 37.4% of intake patients declined and 8.1% deferred therapy - decisions shaped by preference and practicality as much as by medicine.

From Europe, Agosta et al. (2026) report the first year of lecanemab and donanemab delivery at an Italian tertiary memory centre (29 treatment courses), demonstrating both feasibility and the intensity

of the monitoring workload. Filippi et al. (2026) distill early frontline lessons into three domains: patient selection must integrate cognitive, functional, and biological data beyond rigid score thresholds; safety monitoring must balance ARIA risk against real-world feasibility; and successful implementation depends on “transparent communication and continuous shared decision-making, particularly when benefit is uncertain or safety events occur.” Together these papers justify AD-Profile’s focus on treatment burden, monitoring logistics, and communication preferences.

2.3 Decision Support and Knowledge Translation in Dementia

Biard et al. (2025) conducted an umbrella review of knowledge-translation interventions supporting decision-making for people living with dementia and their care partners. It was the single richest source in our review (30 extracted quotes), covering advance care planning, caregiver involvement, tailored plain-language information, and the timing and format of information delivery. Bogza et al. (2020) designed and evaluated a web-based decision aid for older adults with mild cognitive impairment through six user-centered design rounds with clinicians and patients. Their findings shaped many of our interface decisions directly: guide the user step by step and tailor content to their priorities; keep content “simple but not simplistic” using information layering, plain language, and pictograms; keep definitions beside the question rather than on separate pages; prefer checkboxes over drop-down menus; and avoid overwhelming users, their clinician participants specifically flagged that too many ranked priority items with complex wording burden users, which motivated our strict 20-question limit.

2.4 Co-Design and Visual Communication in Health

Dunn et al. (2026) reflect on practicing co-design for clinical-trial communication aids, cataloguing the challenges of designing with busy medical stakeholders and recommending strongly scaffolded, purpose-focused sessions; recommendations that informed the facilitation structure of our co-design protocol (Section 3.6). Gruters et al. (2021) developed and piloted an interactive visual tool for communicating neuropsychological test results in memory clinics through an iterative three-phase, multi-method process (brainstorms, think-aloud sessions, focus groups), demonstrating both the value and the method of iteratively presenting complex clinical information to memory-clinic populations.

2.5 The Gap AD-Profile Addresses

Across all eleven papers a consistent picture emerges: the anti-amyloid treatment decision is high-burden, value-laden, and practically constrained; the deciding factors live largely outside the clinical record; and existing tools are either full decision aids (which recommend and deliberate) or clinician-facing result visualizations. None of the reviewed work provides a lightweight, pre-appointment instrument that captures the patient’s own practical and personal context and hands the clinician a structured profile. That is the niche AD-Profile occupies.

3. Methods

3.1 Overview and Timeline

The studentship ran from May 1 to August 31, 2026 and was organized into four sequential phases, each producing a concrete artifact that fed the next. Table 1 summarizes the timeline.

Table 1. Project phases and artifacts (summer 2026).

Phase	Dates	Activity	Artifact
1	May 1 - June 15	Research ethics application (IRISS)	Full ethics application REB26-0844, incl. co-design protocol
2	June 15 - July 14	Structured literature review of 11 papers	196-quote evidence spreadsheet + 14-concept taxonomy
3	July 14 - July 29	Question development and shortlisting	80-question bank → 20 shortlisted questions
4	Aug 1 - Aug 11	UI design (20 mockups) and full-stack implementation	Deployed AD-Profile web platform
-	Aug 11 - end of Aug	Reporting and handover	This report

3.2 Phase 1: Research Ethics Application (May 1 - June 15)

The first six weeks were spent understanding the project's scope and preparing the research ethics application through the University of Calgary's IRISS system for review by the Conjoint Faculties Research Ethics Board (CFREB). As my first exposure to formal research ethics, this phase involved learning the Tri-Council Policy Statement (TCPS 2) principles; informed consent, voluntariness, privacy and confidentiality, risk-benefit assessment, and translating the project's plans into the application's many structured sections. The completed application (REB26-0844) specifies:

- **Study design:** a human-centred, iterative co-design study with clinicians to develop a web-based tool supporting treatment discussions in early Alzheimer's disease.
- **Participants:** approximately 25 clinicians (neurologists, geriatricians, geriatric psychiatrists) with experience in early Alzheimer's care, recruited online from Alberta and Ontario through the research team's professional networks, verbal invitations, and snowball sampling, with at most one follow-up contact to avoid pressure.
- **Session protocol:** one-hour online co-design sessions in two formats - (1) individual/paired reflection on information needs, annotation of a prototype, and group share-back; or (2) building-block wireframing on a digital whiteboard - with a researcher-facilitator providing scaffolding rather than soliciting answers (Section 3.6).
- **Consent and withdrawal:** written consent before participation; withdrawal permitted during the session and up to one week afterwards, with direct contributions removed where possible and the group-recording limits of withdrawal explained in advance.
- **Privacy and data management:** recordings transferred immediately from Zoom to a restricted University of Calgary SharePoint folder; identifying information stored separately from study data;

participant IDs used in analysis; de-identified public reporting unless a participant explicitly opts to be acknowledged.

- **Honoraria:** CAD \$200 gift cards; risk assessment concluded minimal risk, limited to mild fatigue and professional-topic discomfort.

Writing this application was slower and more demanding than I anticipated, every methodological choice had to be justified from the participant's perspective, but it forced a precision about the study's goals that paid off in every later phase.

3.3 Phase 2: Structured Literature Review (June 15 - July 14)

The literature review followed a structured quote-extraction protocol, designed and implemented as a shared spreadsheet. For each paper I read, I extracted verbatim quotes carrying decision-relevant evidence and recorded, for every quote: the **article, year, and lead author**; the **quote** itself; **whose perspective** it represents (patients, caregivers, clinicians, or combinations); **who extracted it**; an explicit **"thinking process"** note explaining why the quote matters for the tool; one or more **concept tags**; a **concept explanation**; and one or more **candidate questions to ask** a patient, derived from that evidence.

This discipline, forcing every extracted quote to justify itself with reasoning and to propose a question, is what made the later phases traceable. The concept tags were developed inductively as reading progressed and stabilized into a 14-concept taxonomy (Appendix B): Knowledge-Translation, Values, Treatment-Scheduling, Daily-Life-Impact, Barriers-to-Administration, Barriers-to-Access, Risks, Benefits, Goals, Caregiver-Support, Drug-Eligibility, UI/UX, Cost, and Advance-Care-Planning. In total, **196 quotes** were extracted from the 11 papers, ranging from 13 (Bogza et al., 2020) to 30 (Biard et al., 2025) per paper. Just over half the quotes (99) represent clinician perspectives, 40 represent patients and caregivers jointly, and the remainder patients alone, caregivers alone, or mixed groups; a balance that let the question bank speak to both sides of the appointment.

This phase took markedly longer than planned. Reading a dense clinical or HCI paper for extraction for the first time, not skimming for a summary, but looking for every decision-relevant sentence and reasoning about it, routinely took days per paper rather than the hours I had budgeted.

3.4 Phase 3: Question Development and Shortlisting (July 14 - July 29)

The question bank was built by systematically converting the taxonomy and candidate questions into structured questionnaire items. Each of the **80 items** records a question ID, category, subcategory, the question text, a response type (Likert scale, multiple choice, multiple select, ranking, free text, or hybrids with free-text detail), the full answer options, a brief rationale, and, critically, the **source rows** in the literature review spreadsheet that justify it. Every question is therefore auditable back to specific published evidence. The 80 items span 12 categories (Appendix C), with the largest shares in Treatment-Scheduling, Barriers-to-Administration, and Knowledge-Translation (8 items each).

Shortlisting to 20 was done against four criteria derived from the literature itself: (1) **respondent burden** - the instrument must stay short and plainly worded for people with cognitive impairment, echoing

Bogza et al.'s (2020) finding that too many complex priority items overwhelm users; (2) **coverage** - retain at least one strong item from each major concept area; (3) **clinical value** - prefer items whose answers a clinician can act on in an appointment; and (4) **non-redundancy** - collapse overlapping items. Two notable editorial changes were made during shortlisting: the accessibility question (Q044) was split into two questions separating disability-related accommodation needs from cultural and religious considerations, so that neither is conflated with the other; and the appointment-agenda question (Q031) was merged with the information-confidence question (Q080) into a single free-text item. The final instrument (Appendix A) contains 9 Likert-scale items, 3 multiple choice, 2 multiple select, 2 multiple select with free text, 1 ranked select, and 3 free-text items, spanning 10 categories.

3.5 Phase 4: Designing and Building the AD-Profile Platform (August 1 - 11)

With the instrument fixed, I designed all 20 question screens as high-fidelity mockups in Canva, establishing the visual identity (teal and red on a calm light-cyan palette), the one-question-per-screen structure, colour-coded Likert options, the progress indicator, and the persistent “Take notes” affordance; and then implemented the complete product as a modern web application. Figure 1 shows a mockup and Figure 2 its implemented counterpart.

1 **Treatment Scheduling**
Overall treatment schedule burden

Take notes

How manageable do regular clinic or hospital visits feel to you over 18 months or longer?

Very manageable Somewhat manageable Unsure Somewhat difficult Very difficult

Next Question >

Figure 1. Canva design mockup of question 1 (treatment schedule burden), defining the visual language of the questionnaire.

AD-Profile

Narrator off Colour-blind off Alex Morgan · Patient Sign out

Question 1 of 20

1 Treatment Scheduling
Overall treatment schedule burden

Take notes

How manageable do regular clinic or hospital visits feel to you over 18 months or longer?

Very manageable Somewhat manageable Unsure Somewhat difficult Very difficult

Next Question >

Figure 2. The same question implemented in the shipped AD-Profile web application.

The technology stack was chosen for production readiness on free-tier infrastructure: **Next.js 15** (App Router) with **React 19** and **TypeScript** for the application; **Supabase (hosted PostgreSQL)** accessed through the supabase-js client for persistence; **bcrypt** password hashing and stateless, HMAC-SHA256-signed, httpOnly session cookies for authentication; and **Vercel** for serverless deployment. Row-level security denies all direct database access, with the server holding the sole service key, and multi-step operations (submission creation and deletion) run as atomic SQL functions. The build began on SQLite for local simplicity and was migrated mid-phase to Supabase when testing revealed that Vercel’s ephemeral, per-instance filesystems cannot support a file database (Section 5.3 details this and other engineering challenges). Development practice included TypeScript strict typing throughout, an automated 29-check end-to-end API smoke test, and manual cross-device testing. Section 4.4 presents the resulting platform, and Appendix D inventories its architecture and features.

3.6 Planned Phase: Clinician Co-Design Sessions (Beyond the Studentship)

The methodology for the next project stage is fully specified in the ethics protocol. One-hour online sessions with 1-10 clinicians each will open with ethics review and verbal consent, ground participants in the tool’s goals, and then run one of two facilitated formats. In **Format 1**, participants first reflect individually or in pairs on prompts such as “What types of preferences and values do you need to know about your patients to support their decision-making?” before annotating the AD-Profile prototype, marking what is important, missing, unnecessary, or misplaced, and sharing reflections back to the group. In **Format 2**, small groups compose their ideal clinician-facing summary from building blocks on a digital whiteboard wireframe. Both formats are designed so that clinicians articulate their information

needs before being anchored by our prototype, an ordering informed by co-design practice recommendations (Dunn et al., 2026). Sessions will be recorded, analyzed, and fed into design iterations of the platform. Approximately 25 clinicians will participate across up to 10 sessions, with recruitment in Alberta and Ontario.

4. Results

4.1 Research Ethics Application

The completed ethics application (REB26-0844) was reviewed by the University of Calgary Conjoint Faculties Research Ethics Board. Beyond clearing the way for the co-design sessions, the application itself is a substantial research artifact: it contains the study rationale and research question, the full two-format co-design session protocol, the demographic questionnaire, recruitment and consent procedures with intermediary safeguards, a complete risk-benefit analysis, and a data-management plan covering recording handling, de-identification limits in group settings, withdrawal windows, retention, and secure storage. The anticipated participant-facing research window in the application (July 2026 - May 2027) extends past the studentship.

4.2 Literature Review Corpus

The full literature review comprises **196 coded evidence quotes from 11 peer-reviewed papers** (2020-2026), spanning clinical trials commentary, health-system reviews, real-world implementation studies, an umbrella review, and HCI design studies. Table 2 summarizes the corpus; Appendix B details the concept taxonomy with per-concept quote counts. Because every quote carries provenance (whose voice it represents), explicit reasoning, and candidate questions, the spreadsheet functions as a reusable evidence base for the project's next stages, not just a reading log.

Table 2. Reviewed papers and quotes extracted from each.

Paper	Venue, year	Theme	Quotes
Bogza et al.	J Med Internet Res, 2020	User-centred design of an MCI decision aid	13
Gruters et al.	J Alzheimer's Dis, 2021	Interactive visual tool for test results	15
Frank et al.	Can Fam Physician, 2024	Anti-amyloid therapy primer for Canada	21
Smith et al. (CCNA)	J Prev Alzheimer's Dis, 2025	Canadian health-system review	21
Biard et al.	Alzheimer's & Dementia, 2025	Umbrella review: decision-making support	30
Mittler et al.	J Neurology, 2025	VA patient journey and decision processes	15
Weiss et al.	CMAJ, 2026	Lecanemab use in Canada after approval	15
Dunn et al.	DIS '26 (ACM), 2026	Co-design challenges and recommendations	16
Agosta et al.	Alzheimer's Res Ther, 2026	1-year real-world implementation (Italy)	16
Filippi et al.	Lancet Reg Health Eur, 2026	Care-pathway transformation lessons	16
Carlisle et al.	Neurol Ther, 2026	Real-world evidence, specialty clinic (US)	18

4.3 The Question Bank: 80 Candidate Items, 20 Shortlisted

Phase 3 produced an 80-item evidence-grounded question bank across 12 categories, and a shortlisted 20-item instrument across 10 categories (Table 3). The shortlist deliberately over-weights **Treatment-Scheduling** (5 items) because the literature is unanimous that visit frequency, scan burden, and pathway complexity are the decisive practical factors; it retains free-text space for the patient's own words

(personal observations, what would make treatment “worth it,” and the appointment agenda); and it closes with the patient’s own priorities so the clinician summary leads with them. The complete instrument, with all answer options, is in Appendix A; the full bank is in Appendix C.

Table 3. Category distribution: 80-item bank versus 20-item shortlist.

Category	In 80-item bank	In 20-item shortlist
Treatment-Scheduling	8	5
Barriers-to-Administration	8	2
Knowledge-Translation	8	1 (merged into appointment-agenda item)
Risks / Benefits	7	2
Barriers-to-Access	7	3 (accessibility split into two items)
Daily-Life-Impact	7	1
Values	7	2
Caregiver-Support	6	2
Goals	6	1 (merged into appointment-agenda item)
Drug-Eligibility	6	1
Cost	5	1
Advance-Care-Planning	5	0

4.4 The AD-Profile Platform

The principal engineering result of the summer is a complete, production-deployed web application. It is live on Vercel with a hosted Supabase PostgreSQL database, works fully on mobile and desktop, and passed its 29-check end-to-end smoke test against the production database. The platform has three user-facing surfaces:

<https://ad-profile-ilab.vercel.app/>

Public home page

The home page (Figure 3) explains the tool’s purpose in plain language and routes users to sign in. The visual identity follows the Canva mockups, with a dynamic light-cyan gradient that follows the cursor.

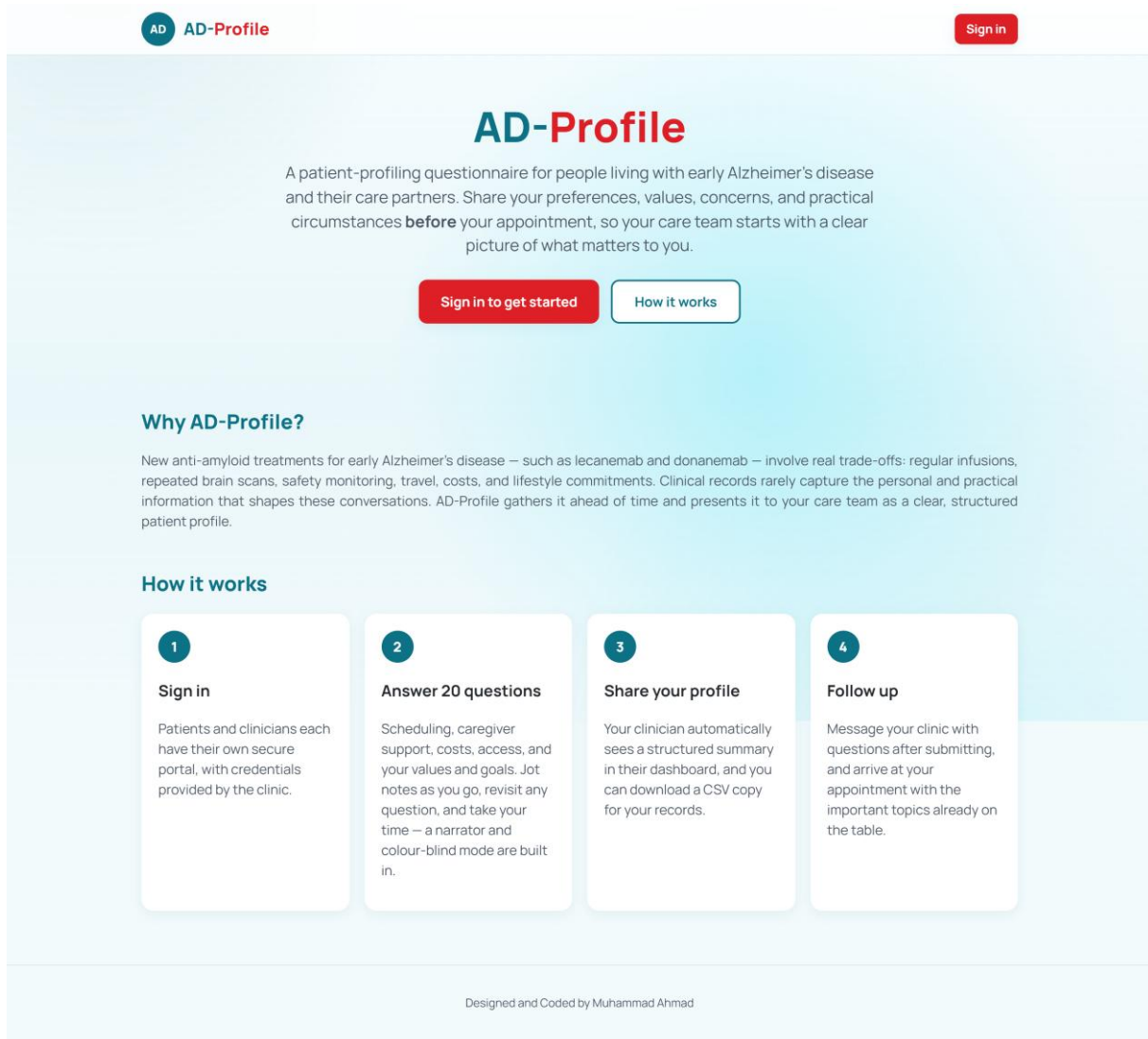


Figure 3. AD-Profile public home page.

Patient questionnaire

After signing in, a patient completes the 20 questions one screen at a time, with a progress bar, back navigation, and autosaved drafts (answers, position, and notes survive page reloads). A persistent “Take notes” panel travels across all 20 questions for anything the patient wants to raise at the appointment; notes are private and are discarded after submission by design. Two accessibility features are built in and appear only during the questionnaire: a **narrator** that reads questions and answers aloud via the browser’s speech synthesis, and a **colour-blind mode** that re-colours the palette and adds unique shape markers to colour-coded options (Figure 4). The ranking question uses a custom pointer-based drag-and-drop that works fluidly with both mouse and touch (Figure 5); the notes panel is shown in Figure 6. On submission the questionnaire locks, and the patient portal offers a CSV download of their answers and a moderated chat with the clinic (Figure 7). The chat enforces a 500-character limit, blocks phone numbers, email addresses, and street addresses to protect against accidental personal-information sharing, and rate-limits messages.

AD

AD-Profile

Narrator off

Colour-blind on

Alex Morgan · Patient

Sign out

Question 1 of 20

1

Treatment Scheduling

Overall treatment schedule burden

Take notes

How manageable do regular clinic or hospital visits feel to you over 18 months or longer?

Very manageable

Somewhat manageable

Unsure

Somewhat difficult

Very difficult

Next Question >

Figure 4. Colour-blind mode: an Okabe-Ito-inspired palette with unique shape markers on each option, toggled from the questionnaire header.

AD

AD-Profile

Narrator off

Colour-blind off

Alex Morgan · Patient

Sign out

Question 16 of 20

16

Barriers to Administration

Sustaining infusions

Take notes

Which part of your regular routine during treatment visits would be hardest to sustain?

Selection

Drag an option into a numbered slot, or tap it to place it in the next open slot. Tap a placed item to remove it. Dropping onto a filled slot swaps the items.

1

Hardest

Travel distance to clinic

2

Going for treatment often

3

Work or family responsibilities

4

Time spent at clinic

5

Easiest

Caregiver availability

Available options

Click or drag from here

< Back

Next Question >

Figure 5. The ranking question (question 16) with its custom pointer-based drag-and-drop; items can be dragged, tapped into slots, swapped, or removed.

AD

AD-Profile

Narrator off

Colour-blind off

16

Barriers to Administration

Sustaining infusions

Which part of your regular routine during treatment would be hardest to sustain?

Selection

Drag an option into a numbered slot, or tap it to place it in the next open slot. Tap a placed item to remove it. Dropping onto a filled slot swaps the items.

Available options

Click or drag from here

1

Hardest

Travel distance to clinic

2

Going for treatment often

3

Work or family responsibilities

4

Time spent at clinic

< Back

My notes

These notes travel with you across all 20 questions – use them for anything you want to remember or raise with your clinician. They are private and will be discarded after you submit the questionnaire.

Ask about how often the MRI scans happen. Bring Sarah to the next appointment.

Done

Figure 6. The global notes panel, available on every question and discarded after submission.

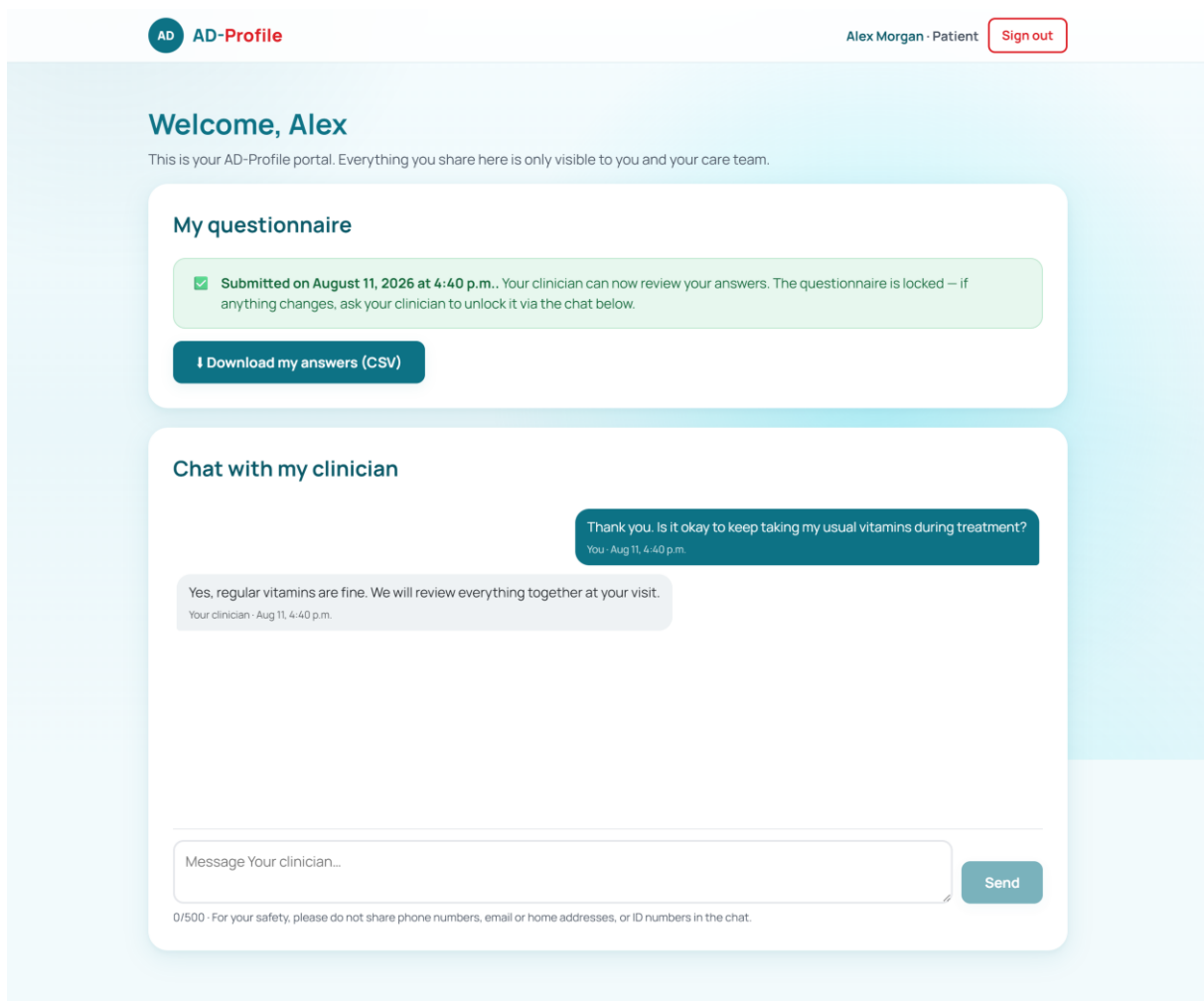


Figure 7. Patient portal after submission: locked questionnaire, CSV download, and the moderated chat with the clinic.

Clinician dashboard

The clinician portal (Figure 8) lists all patients with submission status, unread-message badges, and per-patient actions: open the detailed profile, download the CSV, request a resubmission (which unlocks the patient's questionnaire and shows them the clinician's note), delete a form, create or delete patient accounts, and import a questionnaire CSV on a patient's behalf (for example, one completed on paper and transcribed). The patient detail view (Figure 9) is the clinician-facing summary at the heart of the tool: an at-a-glance strip of **flagged concerns** (answers indicating difficulty, worry, or inability are automatically highlighted), followed by every answer grouped by category with severity-coloured badges, accessibility and accommodation needs surfaced verbatim, the patient's free-text priorities, and the chat thread.

AD

AD-Profile

Clinician

Sign out

Clinician dashboard

Review patient questionnaire summaries before appointments, manage accounts, and answer patient questions.

2

Patients

1

Questionnaires submitted

1

Awaiting submission

1

Unread messages

Add a patient account

Full name

Username

Temporary password (min. 8 characters)

Create account

Import a questionnaire CSV

Upload a CSV that a patient downloaded from AD-Profile (for example, received by email or completed on paper and transcribed). The answers are stored on the server as the patient's current submission.

Patient

Match automatically from the CSV

CSV file

Choose File

No file chosen

Upload and store

Figure 8. Clinician dashboard: patient roster with status, account management, and CSV import.

Quality, security, and deployment

All API routes enforce role-based authorization server-side; passwords are bcrypt-hashed; sessions are stateless HMAC-signed httpOnly cookies; the database denies all public access via row-level security, with the server holding the only key; and submission create/delete run as atomic SQL functions so partial writes cannot occur. The 29-check automated smoke test exercises the full API surface, authentication and rejection paths, submission validation and locking, CSV export/import round-tripping, chat safety filters and rate limits, resubmission flow, and account management, and passes against the deployed production stack. CSV export follows RFC 4180 so files open cleanly in Excel and can be re-imported losslessly.

5. Discussion

5.1 Achievements Against the Original Plan

Measured against the ethics application's two objectives, the summer delivered the complete substrate for objective one (a tool capturing patient and caregiver preferences, values, concerns, and practical constraints) and a strong first iteration of objective two (presenting that information clearly to clinicians). Every planned pre-participant artifact exists: an approved-for-review ethics protocol, a traceable evidence base, a shortlisted instrument, and - beyond what a typical prototype stage requires - a deployed, tested, accessible product rather than a mockup. The co-design sessions will therefore begin from a working system that participants can actually click through, which the co-design literature suggests elicits far more concrete feedback than paper concepts (Dunn et al., 2026).

5.2 What Was Not Possible This Summer

The most significant planned activity that did not happen within the studentship is the **clinician co-design sessions** themselves. This was more so a scheduling reality rather than a failure: the ethics application's anticipated participant window (July 2026 - May 2027) extends past my August 31 end date; clinician recruitment through professional networks takes weeks; and the sessions are only worth running once there is something concrete to co-design around - which the platform now provides. My supervisor, Dr. Rajabiyazdi, will run the sessions during the coming academic year with the research team. Consequently, downstream activities; analysis of co-design data, design iterations informed by clinician feedback, and any patient- or caregiver-facing evaluation, also remain future work. The questionnaire content, while evidence-derived and team-reviewed, has not yet been validated with clinicians or patients, and the clinician summary layout reflects our design judgement pending co-design input.

5.3 Challenges and Lessons Learned

Research-process challenges

The ethics application demanded a level of anticipatory detail I had never practiced, justifying sample sizes, wording withdrawal limits for group recordings, and reasoning about coercion in snowball recruitment, and took the full six weeks. The literature review then took roughly twice as long as I had budgeted: extraction-grade reading is slow, and early on I had to re-read papers as the concept taxonomy stabilized and earlier tagging needed reconciling. The lesson I internalized is that in research, the reading and the paperwork are not overhead around the "real work," they are the work, and they compound: every hour spent on the extraction protocol repaid itself when questions needed evidence trails.

Engineering challenges

Three technical problems were instructive. First, the ranking question's original HTML5 drag-and-drop conflicted with React's re-rendering, freezing the page and leaving items stuck; I rebuilt it on raw pointer

events (pointerdown/move/up) with explicit hit-testing, which made dragging fluid on both mouse and touch and enabled tap-to-place and swap interactions.

Second, deployment to Vercel exposed serverless constraints: the filesystem is read-only except /tmp, and each function instance is isolated and ephemeral. Login initially failed because the app tried to create a data directory in the deployment bundle, and then sessions randomly invalidated because each instance generated its own signing secret - fixed by centralizing writable-path logic and requiring an explicit SESSION_SECRET environment variable.

Third, and most consequentially, the original SQLite database could not work on Vercel at all: a patient's submission would land in one instance's private /tmp and vanish from the next request's view. This forced a mid-build migration to a hosted Supabase PostgreSQL database; rewriting the persistence layer as asynchronous client calls, adding row-level security and atomic SQL functions, and reworking every consumer, after which the full smoke test passed against production. The lesson: architectural assumptions ("the server has a disk") must be validated against the deployment target early, not after features are built.

5.4 Personal Reflections

I came into this studentship with high ambitions and, honestly, an underestimate of the workload. The first month was a firehose: research ethics, TCPS 2, the clinical landscape of anti-amyloid therapy, HCI methods, co-design; practically every day I was learning new information and trying to keep up. The literature review humbled me the most; I expected it to be quick, and it was not, and learning to sit patiently with dense papers, to extract rather than skim, changed how I read. I learned patience and humility as genuine research skills, not clichés: ambition sets the direction, but the day-to-day is careful, slow, cumulative work.

At the same time, the summer showed me the full arc of a research project in a way coursework never had: from an ethics application through evidence synthesis to instrument design to a shipped product. Building AD-Profile end-to-end; design system, accessibility, authentication, database architecture, deployment, debugging production incidents; was one of the most complete piece of software engineering I have done, and doing it inside a research context, where every questionnaire word had to trace back to evidence, gave the engineering a purpose that a class project cannot. I finish the summer with a working product I am proud of, a far more realistic model of how research actually progresses, and a strong desire to see what the clinicians make of it.

5.5 Limitations

- **No participant data yet.** All design decisions to date rest on published literature and team judgement; co-design sessions and any patient-facing evaluation are still to come.
- **The instrument is unvalidated.** The 20 questions are evidence-derived but have not undergone psychometric or comprehension testing with the target population.
- **Demonstration-grade accounts.** The deployment uses seeded demo credentials for evaluation; real clinical use would require proper account provisioning, password reset, audit logging, and a privacy review appropriate to health information.

- **English only.** The literature stresses language and cultural accessibility; the current build does not yet offer translations.
- **Single-clinic model.** The data model assumes one clinician role overseeing all patients; multi-clinic or multi-clinician assignment is future work.
- **Narrator depends on browser voices.** Speech quality varies across devices and browsers.

5.6 Future Work

- Run the clinician co-design sessions (Formats 1 and 2) using the deployed platform as the prototype; analyze and integrate findings into design iterations.
- Extend the clinician summary based on what clinicians say they need first at a glance (the core question of the co-design protocol).
- Add multilingual support and evaluate comprehension with patients and care partners, including people with MCI.
- Harden the platform for real clinical data: provisioning, audit trails, retention policies, and institutional privacy review.
- Explore integration pathways (e.g., exporting the profile into clinic documentation workflows).

6. Conclusion

Over four months, this studentship took AD-Profile from an idea in an ethics application to a deployed, tested, accessible web platform, on a foundation of 196 coded evidence quotes from 11 papers, an 80-item evidence-traceable question bank, and a 20-question shortlisted instrument. The project's central bet, that the missing ingredient in anti-amyloid treatment conversations is structured knowledge of the patient's own preferences, values, concerns, and practical circumstances, is strongly supported by the reviewed literature, where patient interest, burden tolerance, and resources repeatedly decide real-world outcomes. What remains is the project's most important test: putting the tool in front of the clinicians it is designed to serve. Everything they will need for that conversation, the protocol, the evidence, the instrument, and a working product; is now ready for them.

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Appendix A: The 20-Question AD-Profile Instrument

The final shortlisted instrument as implemented in the platform. Each item retains its ID from the 80-question bank, preserving traceability to the literature review evidence rows.

Table 4. The complete AD-Profile questionnaire (20 questions).

#	ID	Category / Subcategory	Question	Type	Answer options
1	Q001	Treatment-Scheduling - Overall treatment schedule burden	How manageable do regular clinic or hospital visits feel to you over 18 months or longer?	Likert scale	Very manageable • Somewhat manageable • Unsure • Somewhat difficult • Very difficult
2	Q002	Treatment-Scheduling - Biweekly infusion burden	If the treatment required visits every 2 weeks, how manageable would that be for you?	Likert scale	Very manageable • Somewhat manageable • Unsure • Somewhat difficult • Very difficult
3	Q003	Treatment-Scheduling - Monthly infusion burden	If the treatment required visits every 4 weeks instead, how manageable would that be for you?	Likert scale	Very manageable • Somewhat manageable • Unsure • Somewhat difficult • Very difficult
4	Q004	Treatment-Scheduling - Scan and monitoring schedule	How manageable would repeated brain scans and checkups be throughout the treatment duration?	Likert scale	Very manageable • Somewhat manageable • Unsure • Somewhat difficult • Very difficult
5	Q052	Barriers-to-Administration - Care pathway complexity	How manageable would the full pathway feel, including screening, testing, infusions, scans, and follow-up?	Likert scale	Very manageable • Somewhat manageable • Unsure • Somewhat difficult • Very difficult
6	Q007	Treatment-Scheduling - Timing around daily responsibilities	How much would treatment appointments interfere with work, caregiving, school, travel, or other regular responsibilities?	Multiple choice	Not at all • A little • Somewhat • A lot • Not sure
7	Q009	Caregiver-Support - Decision involvement	Who would you want involved when making this treatment decision?	Multiple select	Me only • My clinician • Spouse or partner • Adult child • Other family member • Friend • Care partner • Other
8	Q010	Caregiver-Support - Appointment support	Who could act as a caregiver and help you attend appointments, arrange transportation, or remember visit details?	Multiple select	Spouse or partner • Adult child • Other family member • Friend • Paid caregiver • Community service • Not sure
9	Q017	Cost - Cost threshold concern	If you had to pay some treatment-related costs yourself, how much would that affect your willingness to proceed?	Likert scale	No effect • Small effect • Moderate effect • Large effect • I could not proceed (must rely on insurance)
10	Q020	Risks, Benefits - Treatment goal understanding	How interested are you in treatment if the goal is slowing decline, not curing or reversing symptoms?	Likert scale	Very interested • Somewhat interested • Unsure • Not very interested • Not interested
11	Q024	Risks, Benefits - Temporary post-infusion symptoms	If an infusion sometimes made you feel unwell for a short time afterward, how acceptable would that be?	Likert scale	Acceptable • Probably acceptable • Unsure • Probably not acceptable • Not acceptable
12	Q033	Drug-Eligibility - Willingness for eligibility testing	Would you be willing to complete specialist eligibility testing to find out whether this treatment applies to you?	Multiple choice	Yes • Maybe • No • I need more information first
13	Q039	Barriers-to-Access - Travel distance	Would travel distance to a specialist clinic, infusion site, or scan centre make treatment difficult?	Likert scale	Not difficult • A little difficult • Somewhat difficult • Very difficult • Not possible • I need more information first
14	Q044A	Barriers-to-Access - Language and accessibility needs	Do you have any language, hearing, vision, reading, mobility, or other accessibility needs that should be accommodated when information is explained or when attending appointments, scans, or treatment visits?	Multiple select + free text	Language or interpreter support • Hearing support • Vision support • Reading difficulty • Mobility support • Help using online forms or technology • Other • None
15	Q044B	Barriers-to-Access -	Are there any cultural or religious	Multiple select	Cultural considerations • Religious

		Cultural and religious considerations	considerations that should shape how your care team explains treatment information or plans appointments, scans, or treatment visits?	+ free text	considerations • Modesty or privacy considerations • Scheduling around prayer, fasting, holidays, or observances • Preference about who is present during discussions • Other • None
16	Q046	Barriers-to-Administration - Sustaining infusions	Which part of your regular routine during treatment visits would be hardest to sustain?	Ranked select	Going for treatment often • Time spent at clinic • Travel distance to clinic • Caregiver availability • Work or family responsibilities • Other
17	Q070	Values - Treatment format preference	Which treatment format would feel most acceptable to you if options were available?	Multiple choice	Hospital infusion • Local clinic infusion • At-home injection if available • Not sure
18	Q058	Daily-Life-Impact - Personal observations outside records	What personal symptoms, routines, or observations do you track that may not appear in your clinical record?	Free text	Free text response
19	Q068	Values - Worthwhile burden	What would make the treatment feel worth it or not worth it for you personally?	Free text	Free text response
20	Q031, Q080	Goals, Knowledge-Translation - Appointment agenda	What question or topic do you most want to make sure is discussed during your appointment? What information would help you feel more confident about making this decision?	Free text	Free text response

Appendix B: Literature Review Concept Taxonomy

The 14 concepts developed inductively during the literature review, with the number of quotes tagged with each concept (a quote may carry multiple tags). The taxonomy defined the categories of the question bank; the UI/UX concept informed platform design decisions rather than questionnaire content.

Table 5. Concept taxonomy with per-concept quote counts (196 quotes total; multi-tagging permitted).

Concept	Quotes	What it captures
Knowledge-Translation	95	How information should be explained: plain language, detail level, format, timing, checking prior knowledge
Values	80	What matters to the patient: trade-offs, priorities, role in decision-making, risk tolerance
Treatment-Scheduling	73	Visit frequency, infusion schedules, scan/monitoring cadence, pathway timing
Daily-Life-Impact	72	Effects on routines, work, family roles, independence, mobility, driving
Barriers-to-Administration	54	What makes sustaining treatment hard: repeated infusions, monitoring, coordination, urgent response
Barriers-to-Access	52	What makes reaching treatment hard: travel, transportation, referrals, local services, language, digital access
Risks	46	Side effects (incl. ARIA), safety monitoring, urgent follow-up, comfort with risk
Benefits	46	Realistic benefit framing (slowing, not cure), worth of modest benefit, uncertainty of individual benefit
Goals	45	Quality-of-life priorities, definitions of success, appointment agendas, strengths to preserve
Caregiver-Support	45	Who is involved in deciding, attending, monitoring; caregiver observations and agreement
Drug-Eligibility	32	Willingness for eligibility testing, screening context, alternatives if not eligible
UI/UX	27	Interface evidence: guided flows, controls, layering, avoiding overload (informed the platform, not the questions)
Cost	16	Direct and indirect costs, insurance, financial planning
Advance-Care-Planning	11	Future care preferences, decision-maker planning (deferred from the 20-item shortlist)

Quote provenance: 99 quotes reflect clinician perspectives; 40 patients and caregivers jointly; 22 patients and clinicians; 18 patients alone; 9 patients, caregivers, and clinicians; 4 caregivers alone; and 4 caregivers and clinicians.

Appendix C: The 80-Question Bank

The full candidate question bank developed in Phase 3. Every item's rationale and literature source rows are recorded in the project workbook; response options are omitted here for space.

Table 6. All 80 candidate questions by ID, category, and response type.

ID	Category - Subcategory	Question	Type
Q001	Treatment-Scheduling - Overall treatment schedule burden	How manageable would regular clinic or hospital visits feel over 18 months or longer?	Likert scale
Q002	Treatment-Scheduling - Biweekly infusion burden	If treatment required visits every 2 weeks, how manageable would that be for you?	Likert scale
Q003	Treatment-Scheduling - Monthly infusion burden	If treatment required visits every 4 weeks, how manageable would that be for you?	Likert scale
Q004	Treatment-Scheduling - Scan and monitoring schedule	How manageable would repeated brain scans and checkups be during treatment?	Likert scale
Q005	Treatment-Scheduling - Specialist visit feasibility	How manageable would it be for you to attend a specialized memory clinic or specialist appointment if needed?	Likert scale
Q006	Treatment-Scheduling - Preferred treatment location	Where would treatment be easiest for you to receive, if options were available?	Multiple choice
Q007	Treatment-Scheduling - Timing around daily responsibilities	Would treatment appointments interfere with work, caregiving, school, travel, or other regular responsibilities?	Multiple choice
Q008	Treatment-Scheduling - Decision timing	Would you prefer to make a decision during the main visit, or have a separate follow-up visit to decide?	Multiple choice
Q009	Caregiver-Support - Decision involvement	Who would you want involved when making this treatment decision?	Multiple select
Q010	Caregiver-Support - Appointment support	Who could help you attend appointments, arrange transportation, or remember visit details?	Multiple select
Q011	Caregiver-Support - Monitoring and safety support	If treatment caused side effects or urgent concerns, who could help you notice symptoms and contact the care team?	Multiple select
Q012	Caregiver-Support - Care partner observations	Would you want your care partner to share observations about your daily function, mood, memory, or quality of life?	Multiple choice
Q013	Caregiver-Support - Family/caregiver agreement	Are there any disagreements between you and your care partner or family about treatment, support, or future care?	Multiple choice + free text
Q014	Caregiver-Support - Caregiver confidence	What information would help you and your caregiver feel confident about the treatment decision?	Free text
Q015	Cost - Direct treatment cost	Would treatment cost, insurance coverage, or out-of-pocket expenses affect your decision?	Likert scale
Q016	Cost - Indirect costs	Would travel, parking, lodging, time off work, or other indirect costs make treatment difficult?	Likert scale
Q017	Cost - Cost threshold concern	If you had to pay some treatment-related costs yourself, how much would that affect your willingness to proceed?	Likert scale
Q018	Cost - Insurance approval uncertainty	Would uncertainty about insurance or approval make you want to delay the decision?	Multiple choice
Q019	Cost - Financial planning needs	Are financial, legal, or family planning concerns affecting how you think about treatment?	Multiple choice + free text
Q020	Risks, Benefits - Treatment goal understanding	How interested are you in treatment if the goal is slowing decline, not curing or reversing symptoms?	Likert scale
Q021	Risks, Benefits - Worth of modest benefit	How worthwhile would a modest slowing of decline feel to you?	Likert scale
Q022	Risks, Benefits - Comfort with uncertainty	How comfortable are you considering treatment when the benefit for one person may be hard to predict?	Likert scale
Q023	Risks, Benefits - Side-effect concern	How worried are you about possible treatment side effects?	Likert scale
Q024	Risks, Benefits - Temporary post-	If an infusion sometimes made you feel unwell for a short time afterward,	Likert scale

	infusion symptoms	how acceptable would that be?	
Q025	Risks, Benefits - Urgent safety follow-up	If urgent extra scans or visits were needed for safety, how manageable would that be for you?	Likert scale
Q026	Risks, Benefits - Stopping or pausing treatment	If treatment became too risky, too burdensome, or no longer fit your goals, would you want to revisit, pause, or stop it?	Multiple choice
Q027	Goals - Top treatment priorities	What matters most to you when thinking about treatment?	Ranking
Q028	Goals - Personal success definition	What would make treatment feel successful to you?	Multiple select + free text
Q029	Goals - Other care and support goals	Besides anti-amyloid treatment, what other care or support would you want your clinician to discuss?	Multiple select
Q030	Goals - Strengths to preserve	What abilities, routines, or strengths do you most want to preserve?	Free text
Q031	Goals - Appointment agenda	What question or topic do you most want to make sure is discussed during your appointment?	Free text
Q032	Goals - Quality-of-life priority	What quality-of-life goal matters most to you right now?	Free text
Q033	Drug-Eligibility - Willingness for eligibility testing	Would you be willing to complete specialist testing to find out whether this treatment applies to you?	Multiple choice
Q034	Drug-Eligibility - Comfort before knowing eligibility	How comfortable would you be going through testing before knowing whether you are eligible?	Likert scale
Q035	Drug-Eligibility - Eligibility explanation needs	Would you want your clinician to clearly explain why treatment may or may not be suitable for you?	Multiple choice
Q036	Drug-Eligibility - Support during screening	Who could help you complete screening steps, interviews, telemedicine appointments, or longer assessment visits?	Multiple select
Q037	Drug-Eligibility - Test-taking context	Are there language, education, hearing, vision, anxiety, or testing-related factors that could affect how your screening results should be understood?	Multiple select + free text
Q038	Drug-Eligibility - If not eligible	If this treatment is not a good fit, how open would you be to discussing other early Alzheimer's care and support options?	Likert scale
Q039	Barriers-to-Access - Travel distance	Would travel distance to a specialist clinic, infusion site, or scan centre make treatment difficult?	Likert scale
Q040	Barriers-to-Access - Transportation	Do you have reliable transportation for treatment visits, scans, and urgent follow-up if needed?	Multiple choice
Q041	Barriers-to-Access - Local service availability	Are infusion services, timely imaging, and specialist follow-up available close enough to where you live?	Multiple choice
Q042	Barriers-to-Access - Telehealth and remote support	Would telehealth or remote follow-up make it easier for you to access specialist care?	Multiple choice
Q043	Barriers-to-Access - Digital access	Would using an online questionnaire or decision tool create any difficulty for you?	Multiple choice + free text
Q044	Barriers-to-Access - Language and accessibility needs	Do you have language, cultural, religious, hearing, vision, or accessibility needs that should shape how information is explained?	Multiple select
Q045	Barriers-to-Access - Referral access	Did you have any difficulty getting referred to a memory clinic, specialist, or treatment program?	Multiple choice + free text
Q046	Barriers-to-Administration - Sustaining infusions	What part of regular treatment visits would be hardest to sustain?	Multiple select
Q047	Barriers-to-Administration - Sustaining monitoring	What part of repeated monitoring would be hardest for you?	Multiple select
Q048	Barriers-to-Administration - Urgent response ability	If new symptoms appeared during treatment, how quickly could you contact the care team or get urgent imaging?	Multiple choice
Q049	Barriers-to-Administration - Side-effect management	If treatment caused short-term side effects, what support would you need to manage them?	Multiple select + free text
Q050	Barriers-to-Administration - Coordination burden	Would remembering, scheduling, and coordinating all treatment tasks be difficult for you?	Likert scale
Q051	Barriers-to-Administration - At-home administration support	If an at-home injection option became available, what support would you need to manage it safely?	Multiple select
Q052	Barriers-to-Administration - Care pathway complexity	How manageable would the full pathway feel, including screening, testing, infusions, scans, and follow-up?	Likert scale
Q053	Barriers-to-Administration -	Would you want to revisit the treatment decision if the burden became	Multiple choice

	Reconsidering treatment after burden	higher than expected?	
Q054	Daily-Life-Impact - Current daily function	What daily activities are you still managing independently, and where do you need help?	Free text
Q055	Daily-Life-Impact - Routine impact	How would regular appointments, scans, or treatment visits affect your usual routine?	Multiple choice + free text
Q056	Daily-Life-Impact - Work and autonomy	Are you worried about how early Alzheimer's or treatment could affect work, family roles, or long-term independence?	Multiple select
Q057	Daily-Life-Impact - Mobility and safety	Do falls, mobility, home safety, or driving changes affect your comfort with regular treatment visits?	Multiple choice + free text
Q058	Daily-Life-Impact - Personal observations outside records	What personal symptoms, routines, or observations do you track that may not appear in your clinical record?	Free text
Q059	Daily-Life-Impact - Family adjustment	Is there anything your family or care partner is finding difficult to adjust to in daily life?	Free text
Q060	Daily-Life-Impact - Areas needing practical advice	What areas of daily life do you want practical advice for?	Multiple select
Q061	Advance-Care-Planning - Future care discussion readiness	Would you like to discuss future treatment and care preferences now while you can be actively involved?	Multiple choice
Q062	Advance-Care-Planning - Topics for future planning	Which future planning topics would you want included in your care discussion?	Multiple select
Q063	Advance-Care-Planning - Decision-maker preferences	Have you thought about who should help make decisions if you cannot make them yourself later?	Multiple choice
Q064	Advance-Care-Planning - Future care goals	Have you discussed your future care goals with family members or health-care providers?	Multiple choice
Q065	Advance-Care-Planning - Continuing treatment over time	What would make you feel that continuing treatment is still worth it over time?	Free text
Q066	Values - Role in decision-making	How involved do you want to be in making this treatment decision?	Multiple choice
Q067	Values - Trade-off preference	Which matters more to you right now?	Multiple choice
Q068	Values - Worthwhile burden	What would make the treatment feel worth it or not worth it for you personally?	Free text
Q069	Values - Risk tolerance	How much uncertainty or risk would you be willing to accept for a chance of slowing decline?	Likert scale
Q070	Values - Treatment format preference	Which treatment format would feel most acceptable to you if options were available?	Multiple choice
Q071	Values - Readiness and motivation	How ready do you feel to commit to the appointments, tests, and follow-up needed for treatment?	Likert scale
Q072	Values - Need time to decide	Would you need more time, family discussion, or more information before deciding?	Multiple choice
Q073	Knowledge-Translation - Preferred detail level	How much detail would you like before your appointment about anti-amyloid treatment?	Multiple choice
Q074	Knowledge-Translation - Plain-language support	Would you like medical words or unfamiliar terms explained in simpler language while you answer the questionnaire?	Multiple choice
Q075	Knowledge-Translation - Risk and benefit explanation style	How would you prefer benefits and risks to be explained?	Multiple choice
Q076	Knowledge-Translation - Topics needing explanation	Which topics do you most want explained before you decide about treatment?	Multiple select
Q077	Knowledge-Translation - Information format	Which format would help you understand and remember treatment information best?	Multiple select
Q078	Knowledge-Translation - Timing of information	When would you prefer to receive treatment information?	Multiple choice
Q079	Knowledge-Translation - Existing knowledge and misinformation	What have you already heard about anti-amyloid treatment?	Free text
Q080	Knowledge-Translation - Confidence after information	What information would help you feel more confident about making this decision?	Free text

Appendix D: Platform Technical Inventory

Technology stack

- **Frontend/backend:** Next.js 15 (App Router) with React 19 and TypeScript; server components for authenticated pages; API route handlers for all data operations.
- **Database:** Supabase-hosted PostgreSQL accessed via supabase-js; citext for case-insensitive usernames; pgcrypto for in-database bcrypt seed hashing; row-level security denies all direct client access (server-only service key); atomic SQL functions create_submission and delete_submission.
- **Authentication:** bcrypt password hashing; stateless HMAC-SHA256-signed session tokens in httpOnly, SameSite cookies; SESSION_SECRET provisioned via environment variable.
- **Deployment:** Vercel (serverless), with the Supabase database as the single source of truth across function instances.
- **Testing:** 29-check end-to-end API smoke test (scripts/smoke-test.mjs) covering authentication, authorization boundaries, validation, submission locking, CSV round-trip, chat safety, resubmission, and account management; manual cross-device testing on desktop and mobile.

Data model

- **users** - role (clinician/patient), display name, bcrypt password hash, questionnaire permission flags (can_fill, resubmit_requested, resubmit_note).
- **submissions** - one active questionnaire submission per patient; answers stored as validated JSON; source marked “portal” or “csv”.
- **messages** - patient-clinician chat with read tracking and timestamps.

Feature inventory

- **Patient:** guided 20-question flow (choice, multi-select with detail fields, pointer-based ranking, free text); progress bar; draft autosave; global notes panel; submission locking; RFC 4180 CSV download; moderated chat.
- **Clinician:** dashboard with roster, status badges, and unread counts; detailed per-patient profile with automatic flagged-concern extraction and severity badges; request-resubmission with note; delete form; create/delete patient accounts; CSV import with validation and automatic patient matching; chat.
- **Accessibility:** Web Speech API narrator; colour-blind mode (recoloured palette plus unique shape markers); ARIA labelling and keyboard operability; toggles scoped to the questionnaire experience; fully responsive layout.
- **Safety:** server-side role checks on every route; chat character limits, personal-information pattern blocking, and rate limiting; questionnaire answer validation server-side against the canonical question definitions.

Demonstration accounts

The deployment is seeded with three evaluation accounts: one clinician (username “clinician”) and two patients (“patient” / Alex Morgan and “patient2” / Jamie Lee). Credentials are displayed on the sign-in page for evaluation purposes and would be removed for any real clinical use.