



Turning patient experience into trusted real-world evidence
Real4Reg Patients Workshop
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Who We Are



Our Mission

PatientsLikeMe exists to close the gap between diagnosis, treatment, and daily life by helping patients navigate their condition, contribute real-world insight, and access the support they need to make meaningful progress.



Our Vision

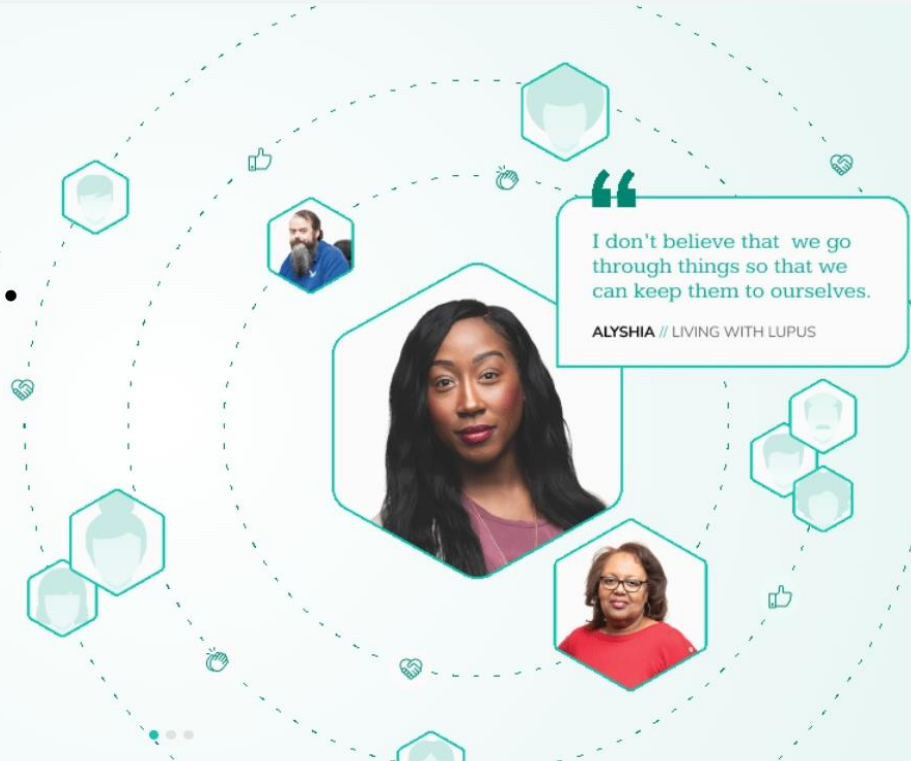
We envision a healthcare system where every patient is continuously supported between clinical encounters, where real-world experience drives better decisions, and where care progression is seamless, personalized, and sustained over time.



PLM helps patients share real experience, learn from peers, and create evidence that improves care.

Find Your Community. Find Your Strength.

Join over 850,000 members harnessing the power of their health insights through shared experience.



Getting started is easy!

I want to...



Meet others like me



Learn about my condition



Track my health



PLM is built on three capabilities that enable personalized digital journeys that drive patient engagement and retention

Community Engagement

Provide members with a safe environment that encourages peer learning and support to decrease isolation, improve emotional wellbeing and build resilience



Connected Health Services

Provide members with access to curated products and services that enable them to better manage their health and improve their quality of life

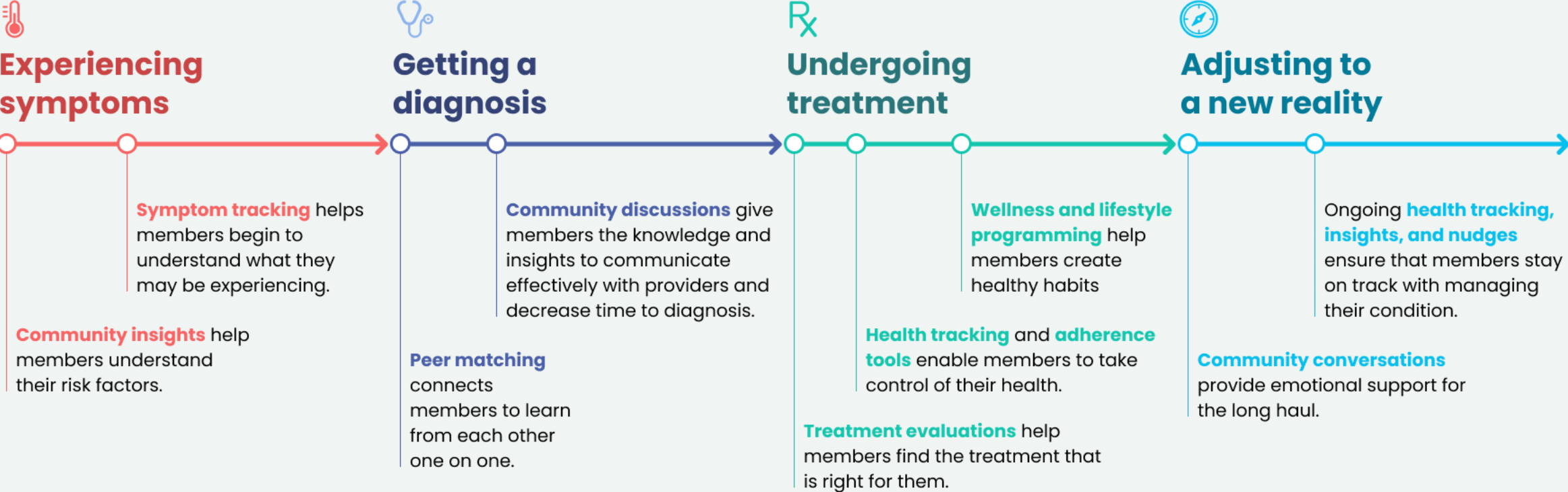
Actionable Health Tools and Insights

Empower members with actionable insights that improves their understanding of their condition, support shared-decision making with their healthcare provider and improve adherence to their care plan



Designed to Empower Patients Across Their Healthcare Journey

Powered by Peer Support and Real-World Insights



Data Combines to Form “MyHealth” Records

Attributes on patients are used for complex analyses and personalized and predicted endpoints



Basic Information
(age, sex, location, interests)

Diseases, Conditions
(early signs, diagnosis status)

General & Specific Symptoms
(onset, severity status)

Treatments & Side Effects
(Rx, OTC, Supp., non-drug)

Quality of Life & Behavior Status
(all conditions, disease specific)

Outcome Measures of Disease
(disease specific)

Patient-generated narrative data from
discussions, journals, feeds

DNA, RNA, Protein, Metabolomics, Lipids,
Metals, Toxins, Immuno-
signature, Sensors, EMR, Claims



PLM's Health Record aggregates patient data into a singular record that allows for longitudinal data capture

Visual Dashboards

Aggregates key health metrics (e.g., symptom severity, PROM scores, medication adherence, mood, sleep) into an at-a-glance interface, enabling patients to:

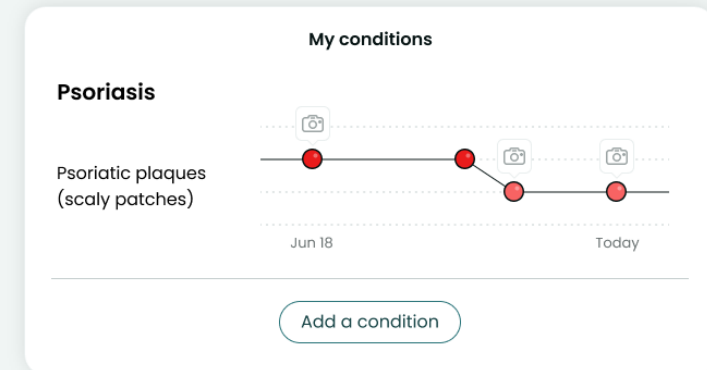
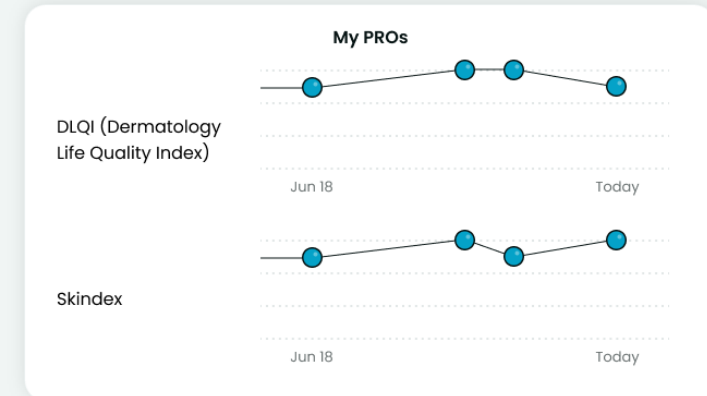
- Recognize patterns over time
- Correlate treatment decisions with symptom improvement
- Identify triggers and flare trends

Chronologically maps:

- Triggers and Symptom evolution
- Medication history
- Behavioral milestones (e.g., goals achieved, educational modules completed)
- Lesion photography archives with date stamps for longitudinal skin monitoring

Provider-Ready Summaries

Patients can generate and share exportable reports—via email or print—to support collaborative care and informed decision-making during clinic visits.



Interactive Tactics Empower Patients to Own Their Health Journey

Actionable Insights

Leverage engagement tactics to turn insights into action. Includes:

- Recent **PROM scores** (e.g., PASI, PHQ-9, DLQI, fatigue, sleep)
- **Symptom trends** over time (e.g., itch, redness, scaling)
- **Medication adherence patterns**
- Representative **lesion images** with date-stamped context

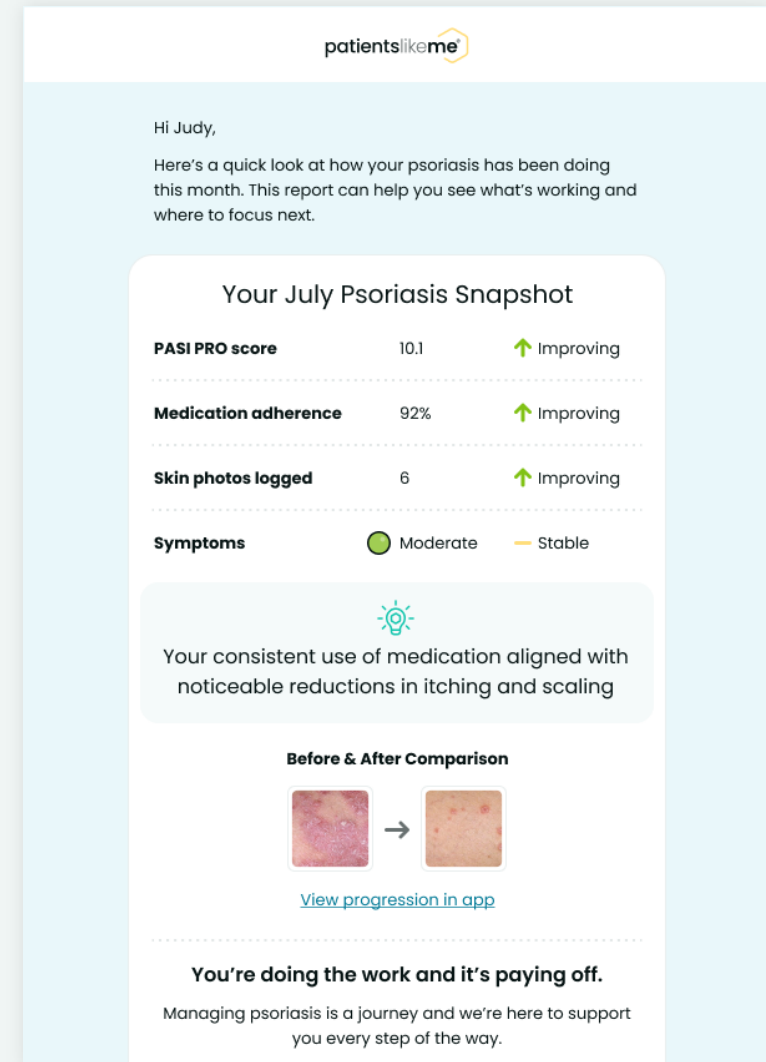
Connecting the Dots

Help the patients see the impact of adherence on psoriasis progression and quality of life

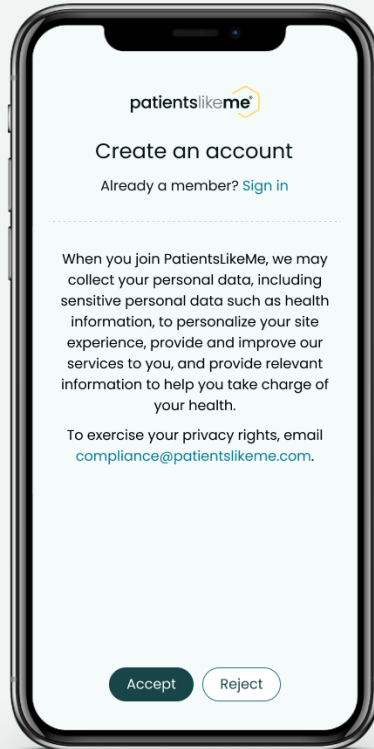
Shared Decision-making Tools

Bridges digital self-management with in-person care. Designed for use during appointments to support:

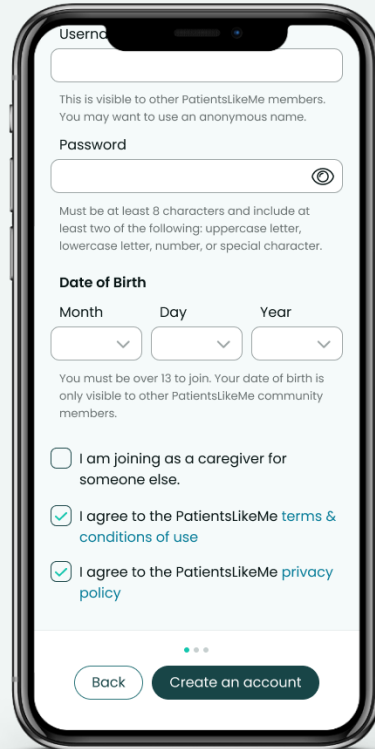
- More informed and time-efficient clinical conversations
- Data-driven adjustments to treatment plans



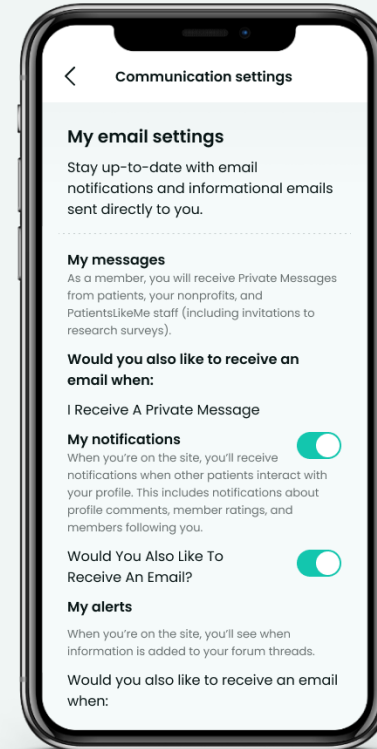
Patient Friendly Consent Process



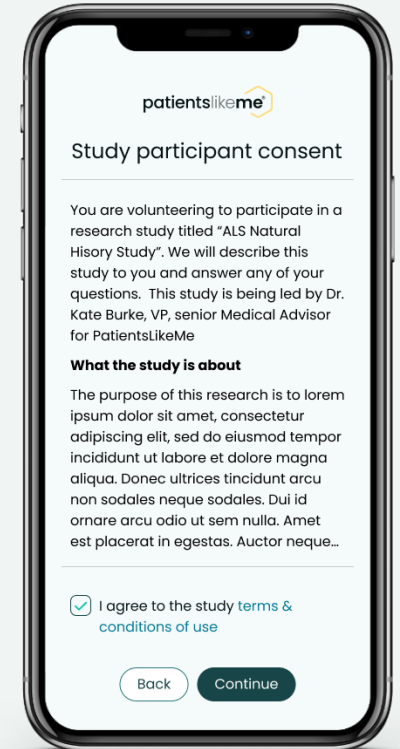
New Users receive dedicated pop-up to consent to personal data collection as part of use of PLM



All new users agree to PLM's Terms of Service and Privacy Practices at Sign-up. This provides consent to contact and share de-identified data with partners



All Users can manage contact preferences on an ongoing basis through privacy settings



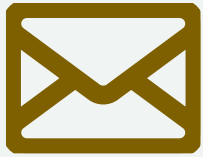
We have dedicated consents for specific programs that users may engage with on PLM

Onboarding / General Consent

Program Specific Consent



PatientsLikeMe has a robust and, transparent, consenting process that enables direct patient communication



Re-contact / Refer

PLM has ability to email users and to make users aware of:

- Products,
- Services
- Research opportunities



Collect Health Data

Users have the ability to track aspects of their health journey through PLM.

This includes collection of:

- User generated information
- Medical Records
- Third party devices



Data Sharing

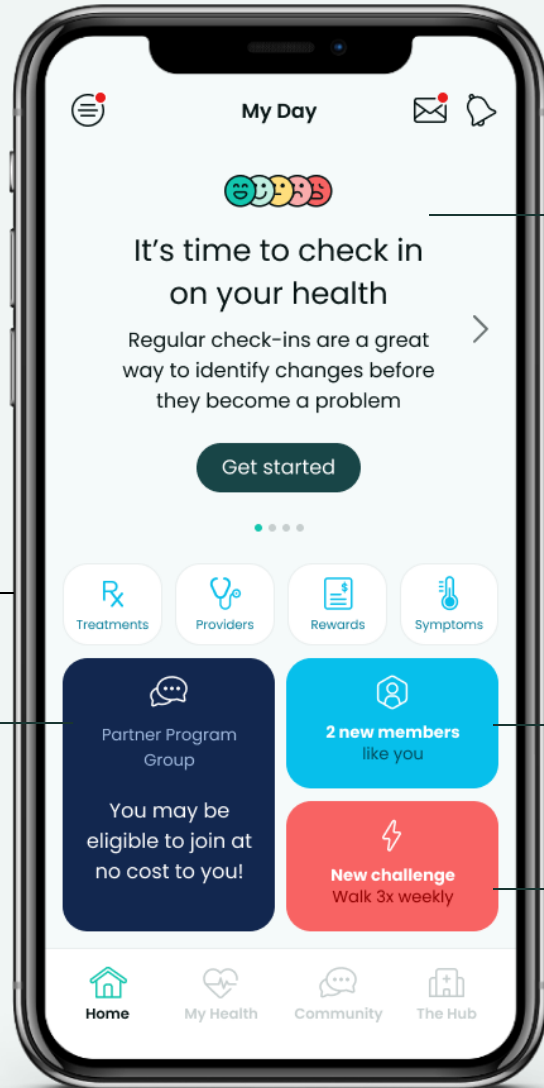
PLM has consent from users to share their deidentified information with its partners

PLM has additional processes to obtain consent to share identifiable information, if needed

Unified Experience Drives Member Engagement And Activation

Connected experience: leverage PLM's integrated experience to create a single platform for members to access your health service solutions

Contextual, Personalized, Promotional Services: Guide members to the covered programs and services that are available to manage their condition(s)



Personalized Health Insights: tailored digital health nudges to promote desired health activities with members

Engaging Community Events: Leverage PLM's peer support to help with behavior change and instilling healthy habits



PatientsLikeMe has demonstrated its ability to engage patients, improve self-efficacy and support better health outcomes

57%


Improved understanding of important factors in treatment decision making

63%

Improved understanding of how to live better with their condition

49%

Learned how to deal with other life problems (stress, work, money, etc.)



Patient-reported benefits of using PLM

Results from a 2016 study of 5,943 patients on PLM platform

52%

Had better conversations with their healthcare professionals

49%

Managed their symptoms better

24%

Became better at taking their medication



Unmet Needs - Minimal success and limitations in ALS Clinical trials

MANY GAPS REMAIN

- Guidance
- Feedback
- Knowledge-base

OBJECTIVE

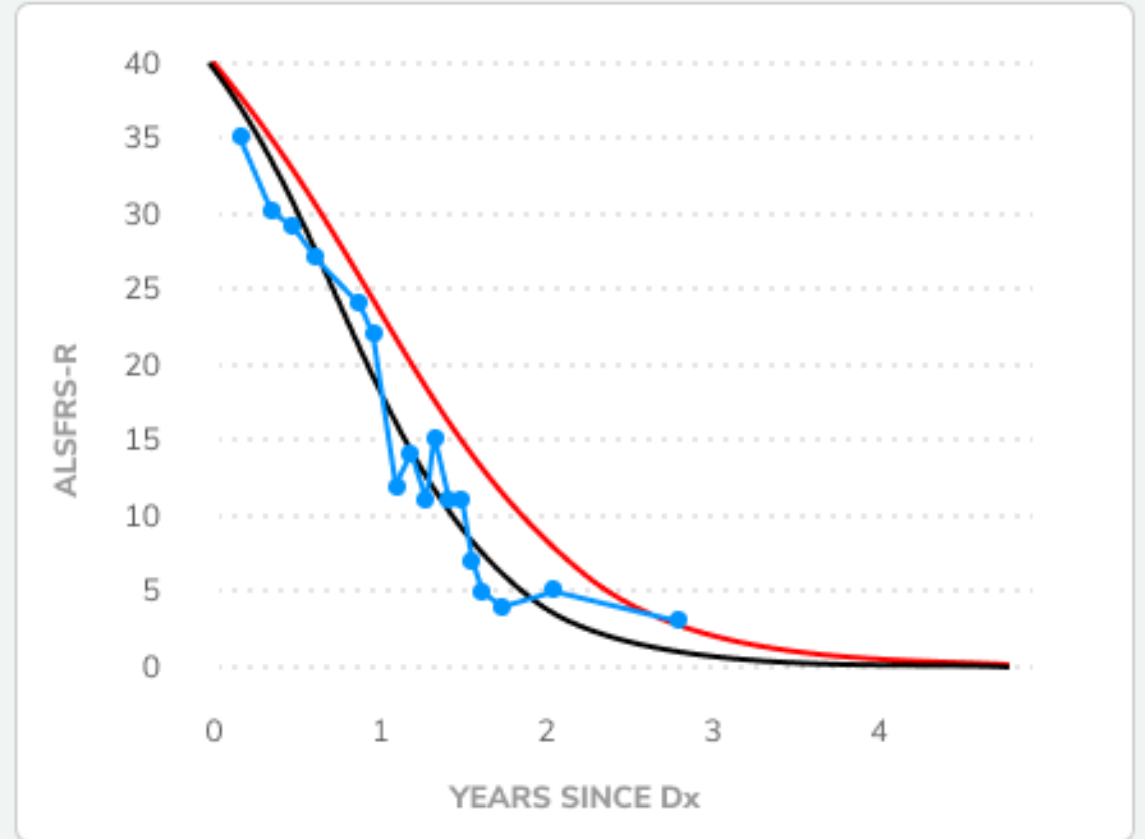
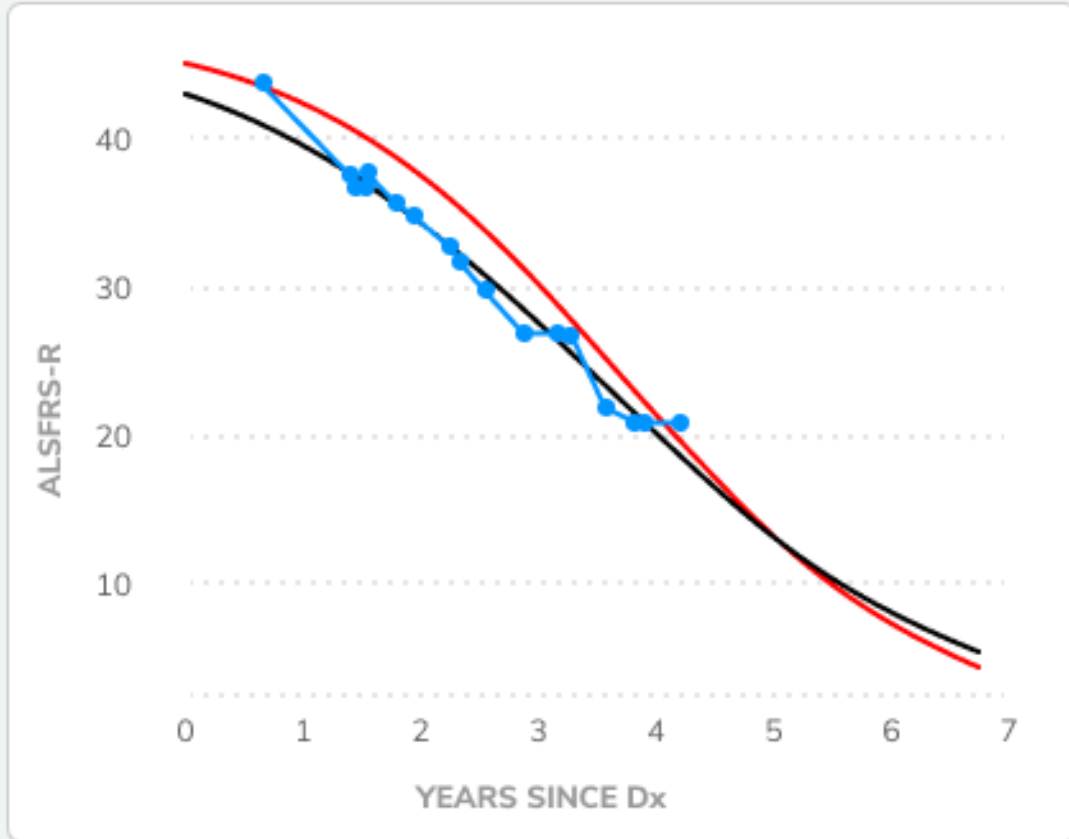
- Provide a platform and process for patients to easily document the treatments they are trying for ALS
 - Perceived effectiveness and side effects,
 - Track the impact on their Revised ALS Functional Rating Scale (ALSFRS-R)



Provide historical matched controls for ALS Clinical Trials

USER IN TREATMENT

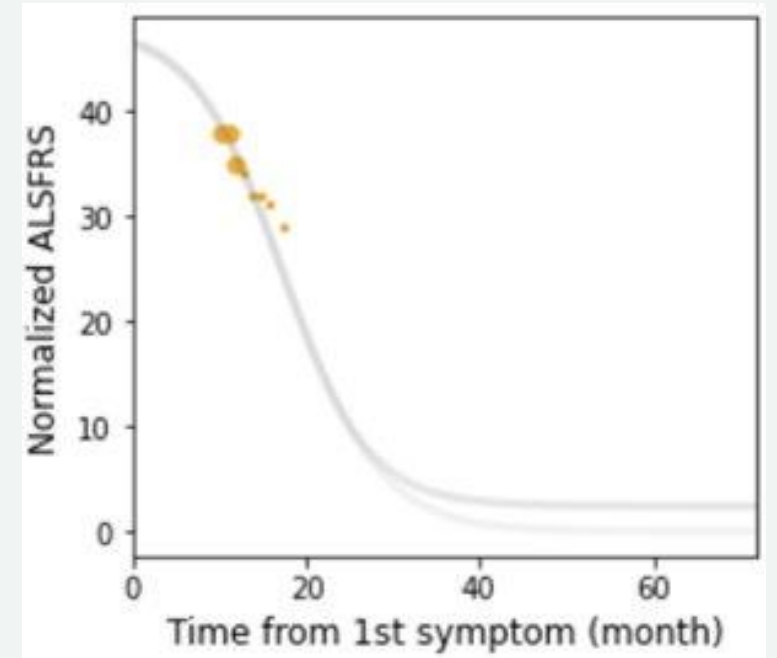
MATCHED CONTROL



— Fitted — Predicted

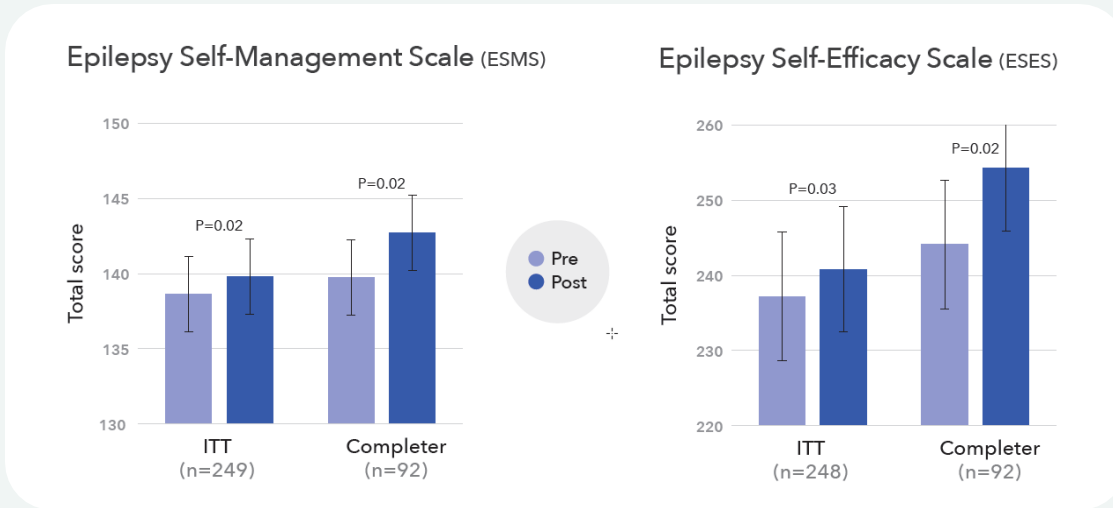
Example of a Patient Matching With PLM Control Data

- PatientsLikeMe can put my experience into context.
- Comparing my individual progression to three matched historical controls when starting a new treatment
- My Data: The 3 orange dots represent my current ALS-FRS scores
- Compare & Predict: The grey lines represent change or progression in ALS-FRS scores over time from three patients with the closest match to me using historical scores

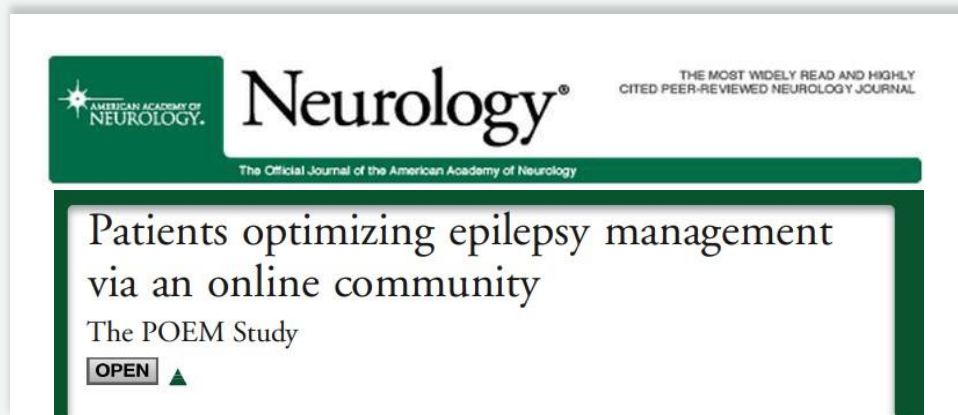


Improving Patient Activation

Activate patients to take care of their own health journey



- Veterans living with seizures due to epilepsy or TBI are isolated, face stigma, and struggle to manage condition
- In a joint study we offered access to the standard PatientsLikeMe platform to ~250 veterans with epilepsy
- After just 6 weeks of interacting with their peers and tracking their seizures, we identified significant improvements in self-efficacy and self-management
- **Impact:** Demonstrated ability of PLM to have patients drive their own healthcare journey



Worked with pharmaceutical manufacturer to enhance patient satisfaction with timely, data-driven and personalized care

Value to Patients



Provided **identifiable, patient-level data** to **Specialty Rx Patient Support Programs**



Patients' perceptions of the program were **high**, including 24/7 nurse phone support and the degree to which patients' needs/concerns were met



It just seems like the nurse who calls me **knew the times I was not feeling great** and I think that **helps with the timeliness** of the phone calls I receive.



75% of patients were extremely likely or likely to continue to share their data

Value to Nurses



Nurses felt that the case reports were **easy to use** and liked that they included **helpful data** regarding the patient's current status such as:

- Side effects
- Symptom changes
- ER visits/hospitalizations
- Free-text information



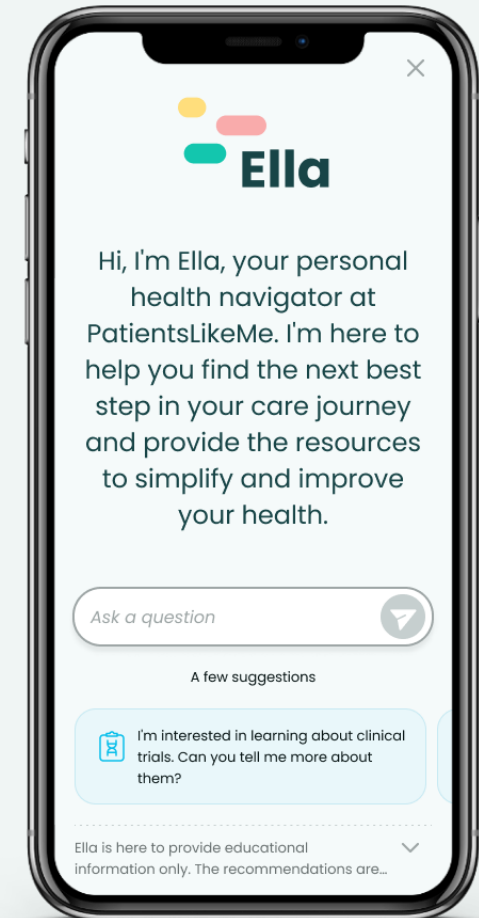
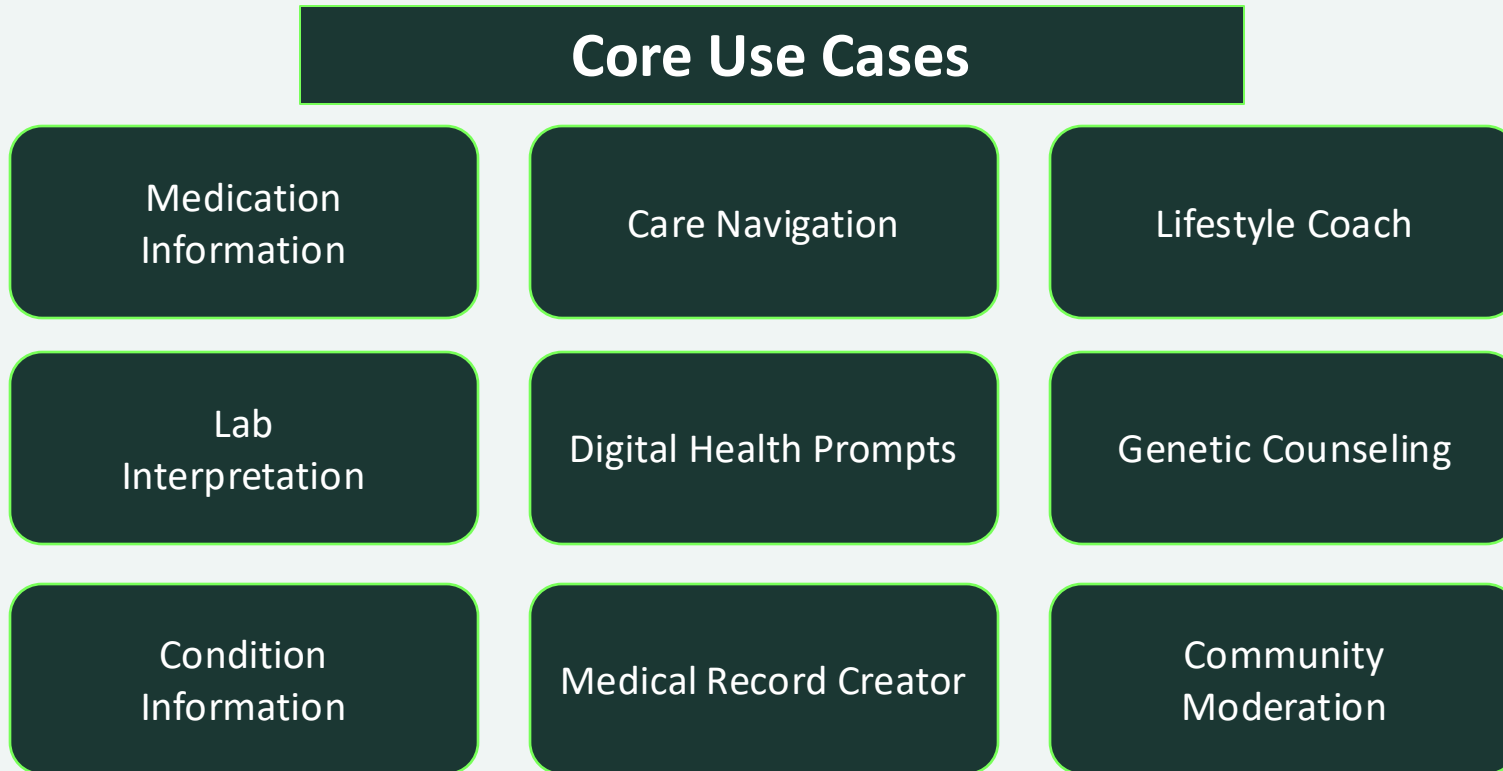
Having the patient data provided nurses with **greater insight into patients' lives**, which in turn enabled a more **organic, patient-led conversation**



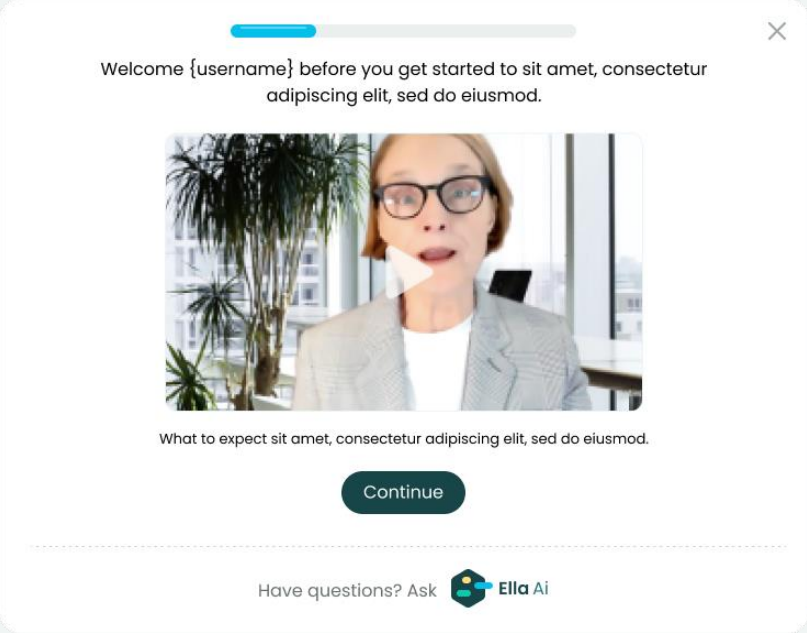
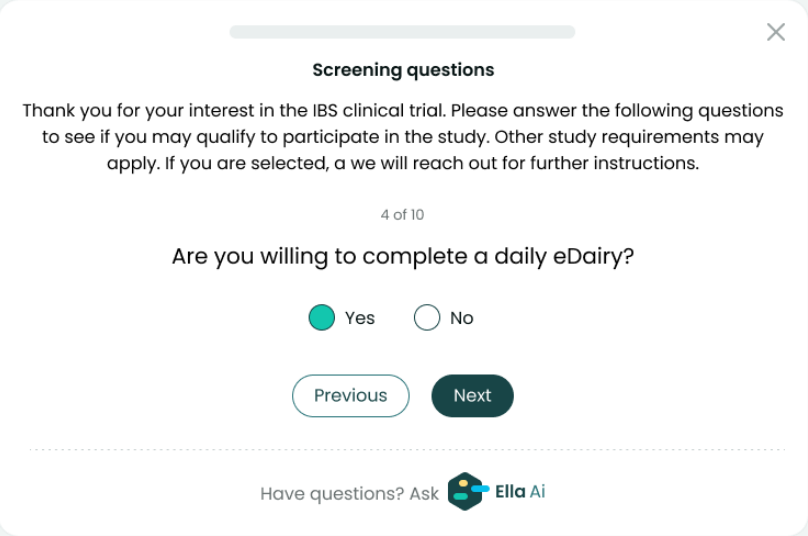
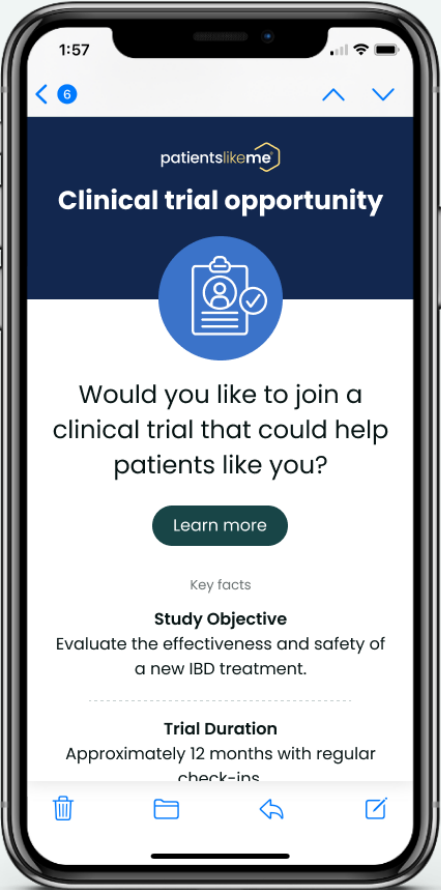
Nurses expressed interest in continuing to use patient data to support patients



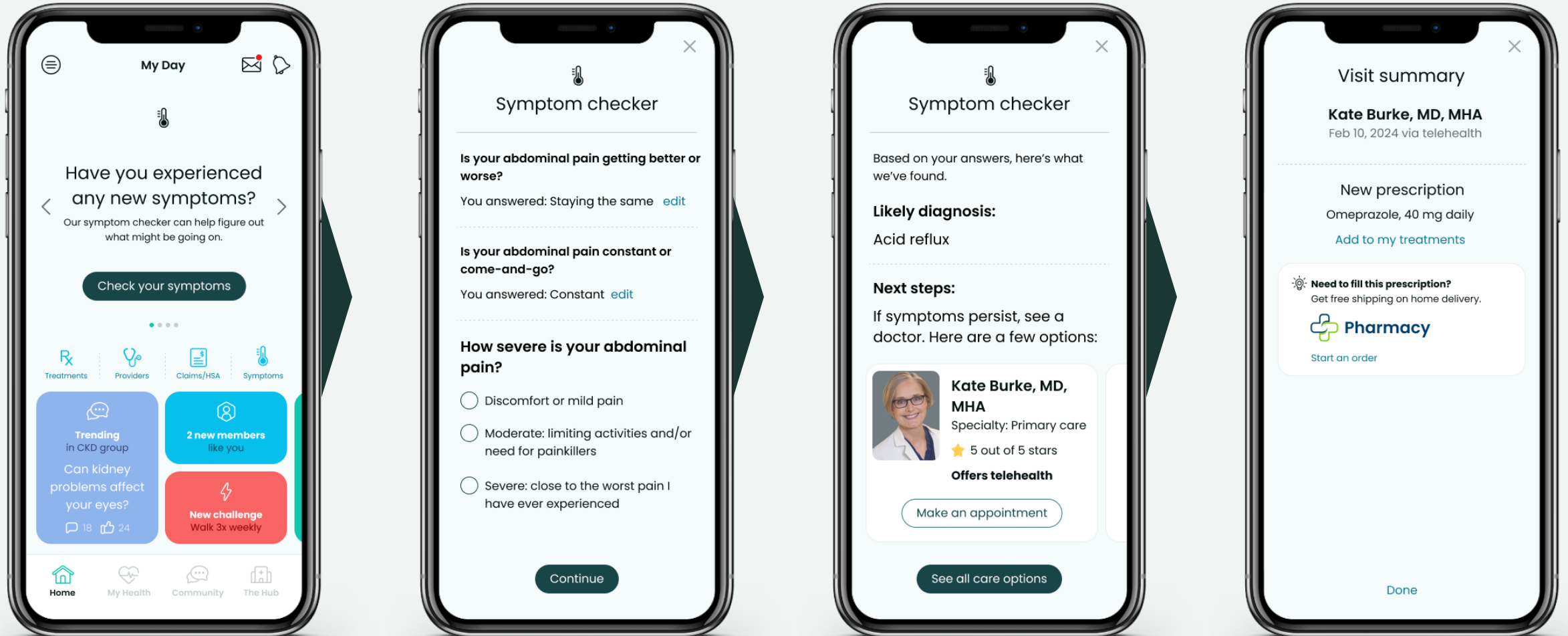
PLM's AI-enabled Health Companion, Ella, provides a scalable platform to collect structured data from patients and navigate to next best health action



Patients can join PatientsLikeMe and participate in various clinical trial opportunities and research studies



And deliver seamless patient experiences that improve access to care and simplify the healthcare experience





"Tracking my symptoms on PLM helped me discuss treatment changes with my doctor and feel less alone."

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