IMPACT OF PARKINSON’S DISEASE

Person with Parkinson’s (PWP)

Care-partners/ Caregivers

Neurologists
Proportion of activities of daily living across time

Time

PWP

Care-partner

CHALLENGES FACED BY PWP AND CARE-TEAM

“(care-partners) feel horrible...challenges dealing with cognitive changes leads to a lot of frustration”

“The risk is that the primary care-partner becomes the 24/7 caregiver”

“...most of the time (the neurologist’s appointment) is 10-15 minutes...in a stimulated environment”
ABOUT THE PROJECT

- Current tools are unidimensional
- Lack data-rich communication with care-team
- Lack of empowerment of PWP and care-team
- Aim to establish data-rich messaging channel between care-team and PWPs
- If successful, our tool may serve as blueprint for other chronic illnesses
IMPACT-PD

Improving Messaging between Patients And their Care Team in Parkinson’s Disease

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THE TEAM

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PD IS HIGHLY VARIABLE

Onset of motor symptoms

Diagnosis of Parkinson's

Early-stage

Mid-stage

Late-stage Institutionalization

Death

Degree of disability

Time (years)

Motor symptoms

Non-motor symptoms

Prodromal

REM sleep behavior disorder

Depression

Anxiety

Excessive daytime sleepiness

Bradykinesia

Rigidity

Tremor

Fluctuations

Dyskinesias

Dysphagia

Axial deformities

Falls

Mild cognitive impairment

Fatigue

Apathy

Orthostatic hypotension

Urinary symptoms

Pain

Psychotic symptoms (visual hallucinations)

Postural instability and gait disorder

Dementia

Adapted from Poewe et al. (2017)
# UNDERSTANDING STAKEHOLDERS

<table>
<thead>
<tr>
<th>Category</th>
<th>Stakeholders</th>
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<tbody>
<tr>
<td><strong>Policy/Governance</strong></td>
<td>Elected officials</td>
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<tr>
<td></td>
<td>Healthcare systems</td>
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<tr>
<td><strong>Markets</strong></td>
<td>Insurance companies</td>
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<tr>
<td></td>
<td>Pharmaceuticals/medical device manufacturers</td>
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<tr>
<td><strong>Environment</strong></td>
<td>Society</td>
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<tr>
<td></td>
<td>Co-workers/colleagues</td>
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<td><strong>Support Network</strong></td>
<td>Caregivers</td>
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<td>Family/Friends</td>
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<td><strong>Individuals</strong></td>
<td>Persons with Parkinson’s (PWPs)</td>
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<td>Clinicians</td>
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<td></td>
<td>Care-partners</td>
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PAIN POINTS HIGHLIGHTED BY STAKEHOLDERS

NEUROLOGISTS
- Time consuming
- Too much data
- Unusable data
- Not integrated with medical record
- Compliance

PWPs
- See the neurologists 1-2x’s a year
- Do not meet on patients’ terms
- Get advice based on half picture
- No data about daily symptoms

CAREGIVER/ CARE-PARTNER
- No input from them in symptom monitoring
- Low level interaction with neurologist
- Patient seen in stimulating environment
- Difficult understanding cognitive decline
- No data about daily symptoms
AIM 1:

- Evaluated current mobile applications for PD on iOS and Google Play
- Conducting survey of PWPs, care-partners/caregivers, and neurologists regarding symptom tracking and technology use
IDENTIFIED LIMITATIONS

**QUANTITATIVE DATA**
Lack of measurable quantitative symptom data that is reliable, accurate, continuous, and accessible

**NON-MOTOR SYMPTOMS**
Cognitive assessments, Quality of Life measures, Mood, Sleep, etc.

**COMMUNICATION**
Between PWPs, care-partners/caregivers, and neurologists

![Bar chart showing symptoms and their impact on QoL and ratio of monitoring to QoL](chart.png)
CURRENT APPS

- ~125 Apps useful for PD:
  - 69 Specifically designed for PD
  - 29 Assessments
  - 23 Informational
  - 13 treatments
  - 4 Assessment/Treatment
MOBILE APP REVIEW SUMMARY

<table>
<thead>
<tr>
<th>Distribution of apps</th>
<th>iOS</th>
<th>GooglePlay</th>
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<tr>
<td>27</td>
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<tr>
<td>Both</td>
<td>36</td>
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110 Total Applications

- 40 Specifically for PD
- 70 Not specifically for PD
PROPOSED SOLUTION: MOBILE APPLICATION
OUR TIMELINE

START

AIM 1-1 EVAULATE

AIM 1-2 CREATE/DESIGN

AIM 2 PILOTING

AIM 3 LONG TERM PILOTING

FUTURE ITERATIONS
TAKEAWAYS

- Lacks reliable, accurate, continuous, accessible measures
- Establish multi-stakeholder data-rich communication channel for PWPs and careteam
- If successful, our solution can be expanded to other chronic conditions
LIMITATIONS

- SURVEY DATA
- SATURATED MARKET
- TIME CONSUMING
OUR PARTNERS

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