# DRIVE™

**Research to Understand the Behavioural Drivers and the Subconscious Influences of Treatment Decisions in Parkinson's Disease**

# Executive summary

**An estimated 40-50% of patients drop off dopamine agonists (DA) in the first 3 months[1]. This was previously believed to be primarily an adherence problem.**

However, behavioural science suggests that "most of decision-making happens" at a subconscious level and that people are not very good at articulating why they did what they did. We needed to look beyond conventional understanding to know the real drivers of these drop off decisions.

Rather than resorting to claim based research, an innovative game-based behavioural research technique (aimed at overcoming biases of claim-based research) was used. Conducted among people living with Parkinson's Disease (PD) caregivers and physicians has provided new insights into treatment choices and decision making:

- The overall context of Parkinson's Disease is one of certain loss and there is high degree of uncertainty regarding treatment choice outcomes.

- As there are no objective measures for evaluating wellbeing, the assessments of tolerability and effectiveness of treatment are mostly subjective.

- The costs/benefits that patients trade-off in making treatment choices are largely ambiguous leading to a general orientation of openness to trial & experimentation across the entire treatment journey.

The problem of treatment in PD is one of lack of preference to treatments rather than one of adherence.

Patient preference for their experience on treatment with Parkinson's Disease can be driven by:

1. Improving coping ability of patients by priming their expectations related to their experience on treatments and any potential outcomes

2. Facilitating self-segmentation, so that patients can find people like them based on factors they deem important rather than an externally imposed factor like demographics or disease stage.

3. Helping patients measure, track and contribute to their subjective wellbeing. This would bring objectivity into play.

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**1.** UCB Market Research - Data on file.

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# PARKINSON'S TREATMENT CONTEXT

## Parkinson's disease is a neurodegenerative progressive condition, and, today, there is no cure.

Living with PD is emotionally and physically challenging, since beyond the physical symptoms, Parkinson's[2] has an impact on a person's life, relationships and sense of self.

The goal of medical management of PD is to provide control of signs and symptoms for as long as possible while minimising adverse effects, and to improve morbidity and quality of life of people living with PD. Symptomatic medications usually provide good control of motor signs of PD for 4-6 years. After this, the disability often progresses.[3]

Along their journey, patients' evolving conditions will require adjustment using various treatment options across 3 main therapeutic classes - Levodopa coupled with carbidopa, Monoamine oxidase - B (MAO-B) Inhibitors, and Dopamine Agonist (DA); specifically, there is a drop off observed with DAs (~40-50%) within the first 3 months[1] which is thought to be related to treatment adherence issues.

1. UCB Market Research - Data on file.
2. Niedenthal J et al. The lived experience of Parkinson's disease: insights from people living with the condition and those who support them (STEPTM research). Journal of Parkinson's disease. 201609;6(suppl.1):246-246.
3. http://emedicine.medscape.com/article/1831191-treatment.

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# PROBLEM STATEMENT

Making decisions related to treatment in this context of high uncertainty is as much driven by the real consequences of drug regimen as it is by their perceptions and feelings about condition and drug regimen.

There is a ~40-50% drop off observed with DAs, within the first 3 months[1]. There are a number of behavioural factors that could be driving the drop-off decision. With limited time available from the neurologists and the ability to recall all of the pertinent information shared by them, patient understanding of these behavioural drivers of treatment decisions for patients and physicians will help develop strategies that move beyond conventional adherence improvement programs and interventions.

**There is a ~40-50% drop off observed with DAs, within the first 3 months after treatment initiation.[1]**

# WHY A BEHAVIOURAL SCIENCE BASED APPROACH

**As uncertainty rises, the tendency to rely on heuristics and biases for decision making increases.**

The assumption is that a very large part of patient engagement and treatment decision making is driven by unintentional, unconscious thoughts.

Very few patients admit to missing doses leading to large Say-Do gaps.

There are a number of biases at play that make it difficult for patients to explain their behaviour, so self-reports are inadequate in understanding real drivers of decision-making.

There are a number of biases that come in to play considering the high level of uncertainty that PD brings about due to the nature of the disease itself.

Symptoms, reactions to drugs can vary from patient to patient.

As uncertainty rises, the tendency to rely on Heuristics and Biases for decision making increases.

So, considering the level of uncertainty, subconscious influence, and the role of heuristics and biases, a behavioural science-based approach would offer a much more robust framework to understand the real drivers of treatment decisions.

# WHAT DRIVES DECISION MAKING?

**A behavioural science perspective, there are 3 key elements that drive decision making.**

## CONTEXT
## MENTAL MODELS
## EMOTIONS

### #1

The **Context**, available **Mental Models** and the Emotions we experience in a given situation. These 3 inputs are combined in our appraisal of events (e.g. the story we tell ourselves about situations, events, objects). How we appraise events determines our experienced emotions, from which we are primed to respond.

### #2

**Action Tendencies** are not determined actions, but rather, are tendencies to orient ourselves to a given objective. These two give us the UNDERSTANDING piece of 'why people act the way they do?'

### #3

The third step is to design **Decision Levers** that will help change behaviour. We do this by creating environmental or social interventions that are likely to influence the appraisal process, thereby creating new/different behaviours.

Outcome of Emotions:

**Action Tendencies**

**Decision Levers**

By influencing appraisal, you can influence emotions, and subsequently, change action tendencies.

## Context

Is a subconscious driver of behaviour, e.g.: The way a person drives can change if he/she were to move to a different city. If we need to understand how & why people take the decisions, we need to understand the contextual factors that influence decision making.

## Decision Levers

Are behavioural principles shown to influence behaviour. Among a set of various levers, these offer the most potential in changing future behaviour. They act on our situational appraisal, thereby producing new or different actions.

## Action Tendencies

As a result of our appraisal of a given situation, and the felt emotion we experience, we are primed for particular action tendencies. That is, our attention, our likelihood to act, or not act, is primed for a given aim.

**Decision Levers**

Introducing unfamiliar interventions. Changing signage to human faces increases risk perception.

**Mental Models**

Deeply learned route behaviours + imagined punishment for being late.

# OBJECTIVES OF BEHAVIOURAL RESEARCH

**Behavioural Research aims to understand and predict behaviour reliably through specifically designed methods.**

## #1

**To allow** for the role of relevant heuristics and biases rather than pushing for deliberated and considered responses. By using games and simulated contexts where respondents have to execute decisions under time pressure rather than expressing opinions under time pressure.

## #2

**To minimise** the effect of social desirability, fear of value judgments, high claims of self control by making respondents predict the behaviour of people like them. By taking themselves out of the equation, the respondents reduce their defenses and get responses that are more realistic.

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# WHAT RELEVANT BEHAVIOURAL PRINCIPLES INFLUENCE TREATMENT DECISIONS

## Prospect Theory and Certainty Effect

**Prospect Theory** is a foundational concept of Behavioural Economics. It explains that we value losses and gains differently - *'We hate losses more than we love gains'*. While the financial value may be the same, the perceptual/psychological value is significantly different.

**In the context of PD**
- A Patient living with Parkinson's Disease is in a certain loss mode regarding the disease, however small or large that loss may be. In this situation, people are willing to gamble for uncertain gains.

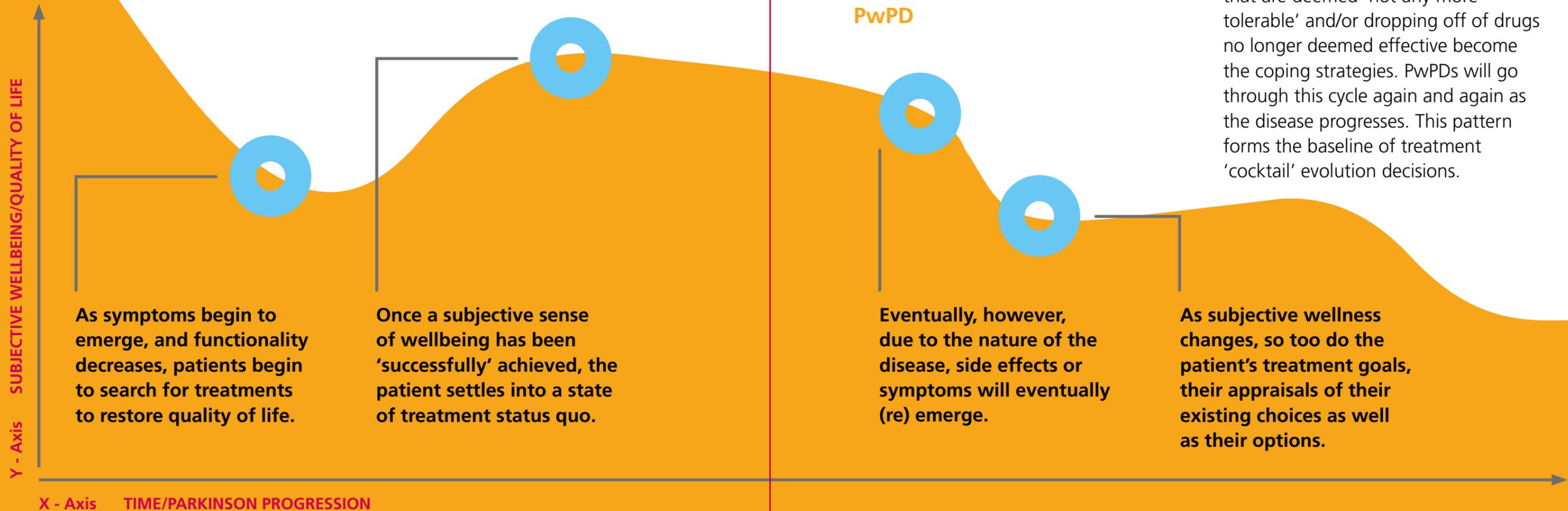For **Certainty Effect**, certain outcomes are weighted more heavily than merely probable outcomes.

**In the context of PD**
- PwPD become extremely loss averse when they experience certain gains (e.g. they deem a drug effective.)
- Hence, we see people holding on to treatment options that come with costs (side effects) even in the face of minimal gain (when that is certain and attributable to the treatment).

# TREATMENT COCKTAIL EVOLUTION

This map illustrates the principles and patterns of the PD treatment evolution. The patterns represented here will be true for every PwPD, and are the underlying, key factors driving treatment evaluation & decision making.

On the Y-axis is 'Quality of Life' as experienced and valued subjectively by the PwPD and on the X-axis is 'time' & the progression of the disease. As quality of life deteriorates, patients are motivated to search for a cure/alternative. Once a 'satisfactory' alternative is found, the patient plateaus in their treatment management. The definition of 'satisfactory' in this case is as unique as the disease itself.

*"It's not a journey, it's an adventure."*
**PwPD**

As long as subjective wellbeing is maintained, so will current treatment management. At some point, however, subjective wellbeing will shift. Either new symptoms will emerge, or previous symptoms will increase in intensity as current treatment becomes less effective, or side effects will emerge. At this point, the patient's treatment goal changes.

New alternative strategies are sought after. Openness to adding drugs to the cocktail, switching away from drugs that are deemed 'not any more tolerable' and/or dropping off of drugs no longer deemed effective become the coping strategies. PwPDs will go through this cycle again and again as the disease progresses. This pattern forms the baseline of treatment 'cocktail' evolution decisions.

**SUBJECTIVE WELLBEING/QUALITY OF LIFE**

**Y - Axis**

**As symptoms begin to emerge, and functionality decreases, patients begin to search for treatments to restore quality of life.**

**Once a subjective sense of wellbeing has been 'successfully' achieved, the patient settles into a state of treatment status quo.**

**Eventually, however, due to the nature of the disease, side effects or symptoms will eventually (re) emerge.**

**As subjective wellness changes, so too do the patient's treatment goals, their appraisals of their existing choices as well as their options.**

**X - Axis    TIME/PARKINSON PROGRESSION**

▷ Quality of life dips, prompting openness to treatment search and uptake.

❚❚ Assuming perceived benefit + tolerability is attained, PwPD enters into a 'holding pattern' with their treatment.

⤬ As the disease progresses, new symptoms, or side effects, may emerge and / or existing treatments may become less effective, prompting a shift back into openness to trials.
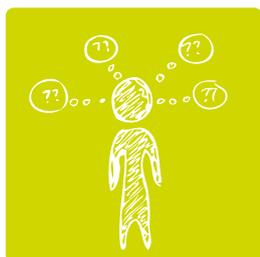
# METHODOLOGY OF DRIVE™ RESEARCH

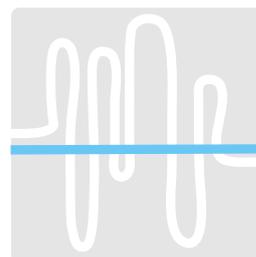The principles behind this behavioural research are as follows:

Decision making is
driven by emotion

## 95%

Behaviour is driven
by subconscious

Context affects
decisions and
behaviour

Heuristics are
efficient shortcuts
or rules of thumb

Rather than conducting standard research through dialogue, to elicit an understanding of need and preference of people living with Parkinson's disease (PwPD), DRIVE™ utilised observation and behavioural science filters to inform and give insight to the conscious and subconscious drivers related to Parkinson's disease medication choice/use decision making. Instead of asking PwPD how they felt or how they would react, they were asked to respond to different options through gamification, which is the process of adding games or gamelike elements to something (such as a task) so as to encourage participation.

In this game, PwPD had to make a choice between scenarios illustrating different real life situations they have faced or could be facing.

# Immersion phase of the research

Patient home visits gave insight as to the conscious drivers in their daily lives and the role that the immediate support system plays in treatment related decision making.

Following these and other in-depth interviews with caregivers, physicians and pharmacists, hypotheses were generated and used mental models and beliefs related to PD treatment. These included treatment initiation, add-on and switch therapy's related decisions, management of the patients' journey and their role in decision making.

Key areas for inquiry included :
- How PwPD evaluate various moments in their treatment journey: what are their goals; their expectations from treatments; defining their coping ability to various challenges; evaluation of role and inputs from various stakeholders?
- How PwPD evaluate effectiveness, tolerability and cost-benefit of medication and the impact this has on adherence to treatment?
- How does medication format/ delivery impact preference?
- How communications and experiences might be framed to resonate with emotional concerns of PwPD (and/or their caregivers)?

- Exploration of preferred sources and channels for trusted information

This led to the creation of a number of scenarios, generated from the interviews and visits. These were used in an online gamified research platform (Ethnolab™) to understand patient's subconscious decision making, in relation to their PD treatment.

Ethnolab™, the property of Final Mile http://finalmile.in/ is a research laboratory used to understand the role of subconscious in the decision-making process to eliminate biases that may occur due to easy availability of logical narratives, or fear of value judgements, or attempts at political correctness. This enables to uncover also what people say they would do versus what they would actually do if they were put in certain situations.

This research tool has been used to analyse the role of subconscious brain i.e. emotions, mental models and context. It looks at the subconscious and the gap that exits between what people say, mean and do, particularly in complex health conditions, in this instance in PD.

61 in depth interviews were conducted across UK, US & France.

81 patients and their caregivers participated to the game based research across these 3 countries.

# The Health Game



**OR**
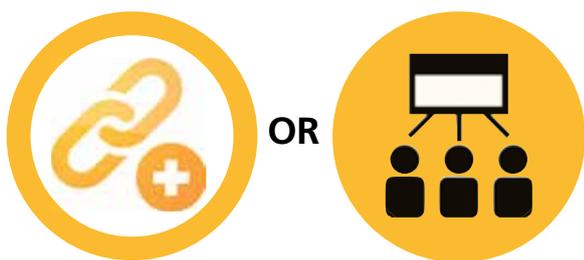


Respondents were provided with a web link to the game and some were invited to a central location.




A unique audio-visual narrative was used and players were informed that 'If you play the game as you would behave in real life, the chances of winning are very high'

Participants used tab or laptop/PC to register their opinion and could only see their own response.




Game exposed participants to multiple choice scenarios, and they were asked to pick 1 out of the 3 options, within a limited time.

Participants were rewarded with points if their responses were in line with the majority of the responses, they were challenged to predict the most popular response in their opponents (or most popular response when posed to 7 people if playing individually rather than in a group).



Discussion followed once 12 such scenarios had been played to review the responses related to the game rounds and discuss correlation with lived experience. Only questions related to scenarios played in the game were presented during discussion.

# DRIVE™ RESEARCH FINDINGS

**Parkinson's Disease
Treatment Evolution Map**



**CONTEXT
OF PD**

Certain
Loss

Uncertain
Outcomes
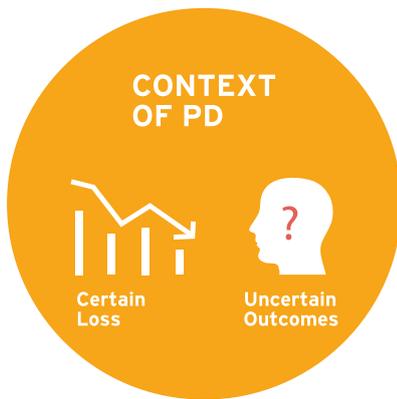
**Drivers influencing
treatment decisions**

PwPD are primed with the certain, degenerative nature of the disease (with visceral images of Parkinson's patients that anchor their expectations).

This state of **Certain Loss** is coupled with high **Uncertainty** regarding specifics of their progression, as well as uncertainty regarding the outcomes of any given treatment option.

# PARKINSON'S IS A CONTEXT OF CERTAIN LOSS

**There is no cure. There is no treatment for the disease. Drugs only manage the symptoms. Drugs can only help for a limited time. Eventually, the disease will overwhelm.**

**In the face of this, PwPD are increasingly willing to gamble on uncertain gains.**

## PROSPECT THEORY & CERTAINTY EFFECT

One of the key characteristics of PD treatment decisions is that PD is a disease context marked by certain loss. Patients are primed by their doctors to understand the disease as a one-way, degenerative experience, with no cure, nothing to slow the progression, nothing to effectively manage the disease itself–treatments may only manage the symptoms.

From a behavioural science perspective, there are two key principles driving treatment decisions over the course of the evolution pattern previously discussed: **Prospect Theory** and **Certainty Effect**.

**Prospect Theory** is a foundational concept of Behavioural Economics. It explains that we value losses and gains differently. It questions the assumptions of utility theory that states that losses and gains are the same. As per prospect theory, while the financial value may be the same, the perceptual/psychological value is significantly different. Our responses might vary significantly depending on whether something is framed as a loss or gain. E.g: Win $10 Vs Don't lose out on $10. The flip side of gambling in the face of certain loss & uncertain gains, is the loss aversion that comes from experiencing certain gains, however small.

In the context of PD, people become extremely loss averse when they experience certain gains (i.e. they deem a drug effective). Hence, we see people holding onto treatment options that come with costs (side effects) even in the face of minimal gain (when that gain is certain & attributable to the treatment).

**Prospect Theory** tells us a few things: We hate losses more than we love gains.

Psychologically, losses are twice as powerful as gains. In the context of PD, a patient is in a certain loss mode regarding the disease, however small or big that loss may be. In this situation, people are willing to gamble for uncertain gains. e.g: If given a choice to a person between losing $25, for sure, and a 30% probability of losing $100 (70% chance of losing nothing), people will gamble. In the context of treatment decisions, it would mean that people are willing to make decisions even if the gains are uncertain.

We hear a number of PwPD talk about how they are willing to try various options and that they are willing to try anything. In simpler terms, the mindset is one of "I got nothing to lose."nothing to lose."

**Subjective Wellbeing** refers to how people experience the quality of their lives, and includes both emotional reactions and cognitive judgments.

No differences observed across the countries, PD stage, genders accross the 3 countries.
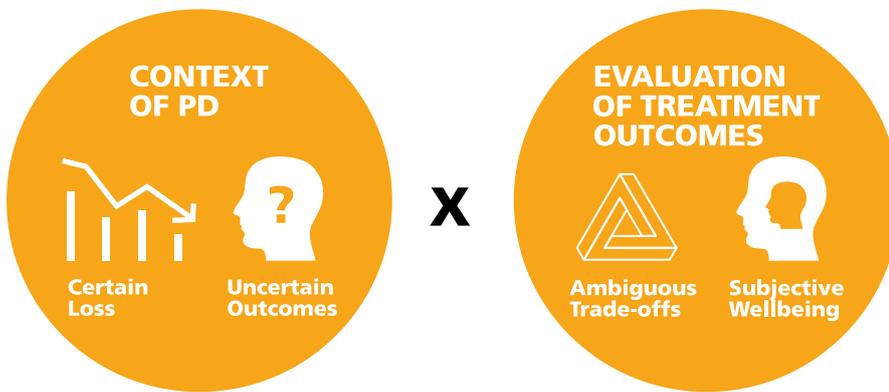
# DRIVERS INFLUENCING TREATMENT DECISIONS

## Subjective Wellbeing:

This treatment context, and experience, is evaluated largely subjectively by PwPD.

What's effective? What's tolerable? It can be difficult to say. In many cases, patients are left to make ambiguous trade-offs between desirable and undesirable aspects of existing treatments and/or between unknown risks of adding or switching treatments.



# THE CONTEXT OF THE DISEASE AND THE ABSENCE OF A CURE LEADS TO AN OPENNESS TO TRIALS

This openness is suspended for periods of time when sufficient effectiveness and sufficient tolerability are attained with a given treatment option.

But, eventually, the disease evolves, pushing people back into an orientation of openness.

# RESPECTIVE INFLUENCE OF PATIENTS AND PHYSICIANS IN TREATMENT DECISION MAKING

In case of first line treatment, decisions are primarily driven by the physician. This is also the case when a PwPD comes in with any requests for additional control leading to an additional treatment by the physician.

The request for treatment change, however, is primarily driven by the patient. In PD, PwPD does not typically drop off treatment. Patients are more often switching treatments rather than 'dropping off' treatment. This happens most often in the cases of side effects that a patient deems unacceptable or not tolerable any more.

*"If in fact you're ok and you're holding - what I call it - you're holding, then leave it alone, unless it's under the strong advice of your specialist."*
**Neurologist**

*"It has to be patient-led in order to get a change in treatment. Neurologist don't offer treatment switch, it's up to the patient to ask."*
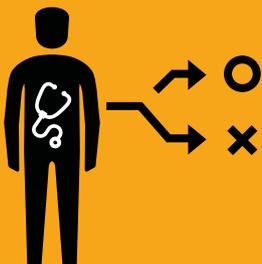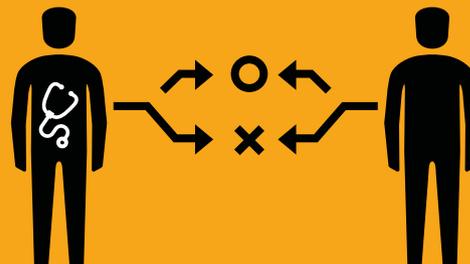**Neurologist**

**First Line Treatment**
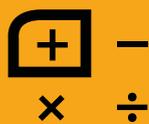
**Adding Treatment**

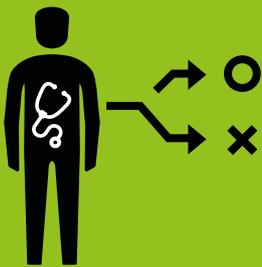**Switching from one treatment option to another**

**Physician-Driven Decision**

**Physician + Patient Shared Decision**

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# EVOLUTION FROM AUTHORITY TO SHARED DECISION MAKING

**FIRST LINE TREATMENT**
Authority Heuristic Led
Decision PwPD Goal:
Manage Symptoms

PwPD: *"I'm experiencing 'X'…
What can you give me?"*
Neurologist: *"Let's try 'Y'"*

**ADDING A TREATMENT**
Authority Heuristic Led
Decision PwPD Goal: Manage
Progression/Efficacy Gap

PwPD: *"I'm still experiencing
symptoms. What can you give me?"*
Neurologist: *"Let's add "Z" and see."*
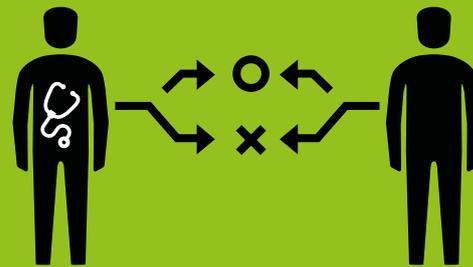
**SWITCHING A TREATMENT**
Patient Led, Deliberate
Decision PwPD Goal: Manage
Progression, Side Effects

PwPD: *"This drug isn't working for
me. I can't tolerate it. What else
can we try?"*

# DRIVE™ RESEARCH FINDINGS SUMMARY

**4 principles driving Patients living with PD orientation to their treatment cocktail evolution**

## #1

The overall context of Parkinson's is one of certain loss.

## #2

There a high degree of uncertainty regarding treatment choice outcomes.

## #3

There are no objective measures for evaluating wellbeing. Tolerability and effectiveness are mostly subjective.

## #4

The costs/ benefits that patients trade-off in making treatment choices are largely ambiguous, leading to a general orientation of openness to trial & experimentation across the entire treatment evolution.

# THERE IS A SHIFTING BALANCE IN DECISION INFLUENCE, BETWEEN SPECIALIST AND PwPD, AS THE TREATMENT COCKTAIL EVOLVES.

**First line and add-on treatment choices are largely initiated by the specialist, in response to efficacy concerns.**

**However, switching between treatment choices, is largely initiated by the PwPD, in response to tolerability issues.**

**As a result, building preference towards their treatment choice can help PwPD maximise value of their treatment options.**

# RECOMMENDATIONS FOR MAXIMISING TREATMENT PATIENT VALUE FOR PATIENTS LIVING WITH PD

**Approach #1**
**FROM 'TRIAL' TO 'STATUS QUO'**

**FROM 'TRIAL' TO 'STATUS QUO'**



Prime Expectations
Roadmap Coping
Ability

Preparing PwPD on what to expect related to the benefits and side-effects related to the drug e.g. Priming Expectations. This set of recommendations is intended to help facilitate the transition from an 'uncertain trial' of a drug, to comfort with the decision of accepting 'status quo' e.g. the existing state or condition.

This is achieved through the use of heuristics as a guide in establishing expectations and coping abilities.

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**Approach #2**
**TRACK & CONTRIBUTE**

**MEASURE, TRACK & CONTRIBUTE**
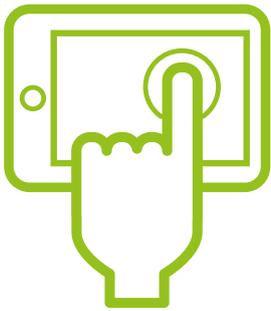


Associate uptake with good data gathering

Opportunities to create objective measures of effectiveness and/or tolerability are provided to help off-set the negative bias of evaluation, being common to subjective wellbeing measures.

**Approach #3**
**SELF SEGMENTATION**

**SELF SEGMENT**



Facilitate Suitability

Considering that PD experience is very different from one patient to the other, instead of using standard parameters like demographics, disease stage or symptoms for segmentation, self-segmentation is recommended for the patients to recognise common parameters.

A PwPD might find more meaningful commonalities with other patients, such as their feeling about the disease, and not their disease state. Facilitating suitability (to be defined) between the common matching connections PwPD may feel can be a more sustainable model.

# IMPLICATIONS OF THE LEARNINGS FROM DRIVE™ RESEARCH

**The learnings from this project lead to question some long held beliefs and alter current views on patient decision making.**

**1.** Patients, as individuals, struggle to fully and accurately articulate why they took a particular decision.

**2.** That when patients say they want more information, they really cannot make full use of that information - What we found is high cognitive load limits their ability to process information.

**3.** There are different dimensions to adherence. It is highly context dependent and in some cases, what may seem like an adherence problem is not one to start with.

4. It is possible to use innovative game based research with patients with severe conditions such as Parkinson.

5. We over-value information over motivation, rationality over emotions in general and more so in the healthcare industry. Merely providing information does not motivate the patient to behave in a particular manner.

6. There is usually a big gap between how a doctor is thinking and how a patient is thinking about treatment decisions.

7. That there are more similarities among patients across countries when it comes to treatment decision making, at least in the Parkinson's context.

8. Visiting patients in their homes and doing research in their natural surroundings can give us much richer insights into their day to day decision making as opposed to talking to them in out of home settings.

9. There are a number of behavioural principles that are relevant in a given treatment context and the main task of research is to arbitrate between those principles. The challenge so far has been that all principles seemed true. With this project we managed to overcome that challenge and identify principles that are pertinent.

Inspired by **patients.**
Driven by **science.**