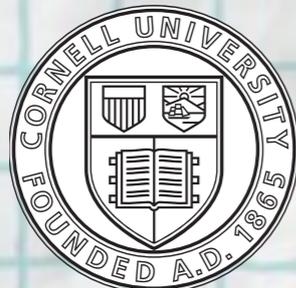


QUANTIFYING THE

changeable SELF

The Role of Self-Tracking in Coming to Terms With and Managing Bipolar Disorder

Mark Matthews, **Elizabeth Murnane**, Jaime Snyder



Goals for today

- Self-tracking motives of people with mental illness
- Personal data practices, benefits, challenges
- Insights into designing personal informatics tools for a mental health context

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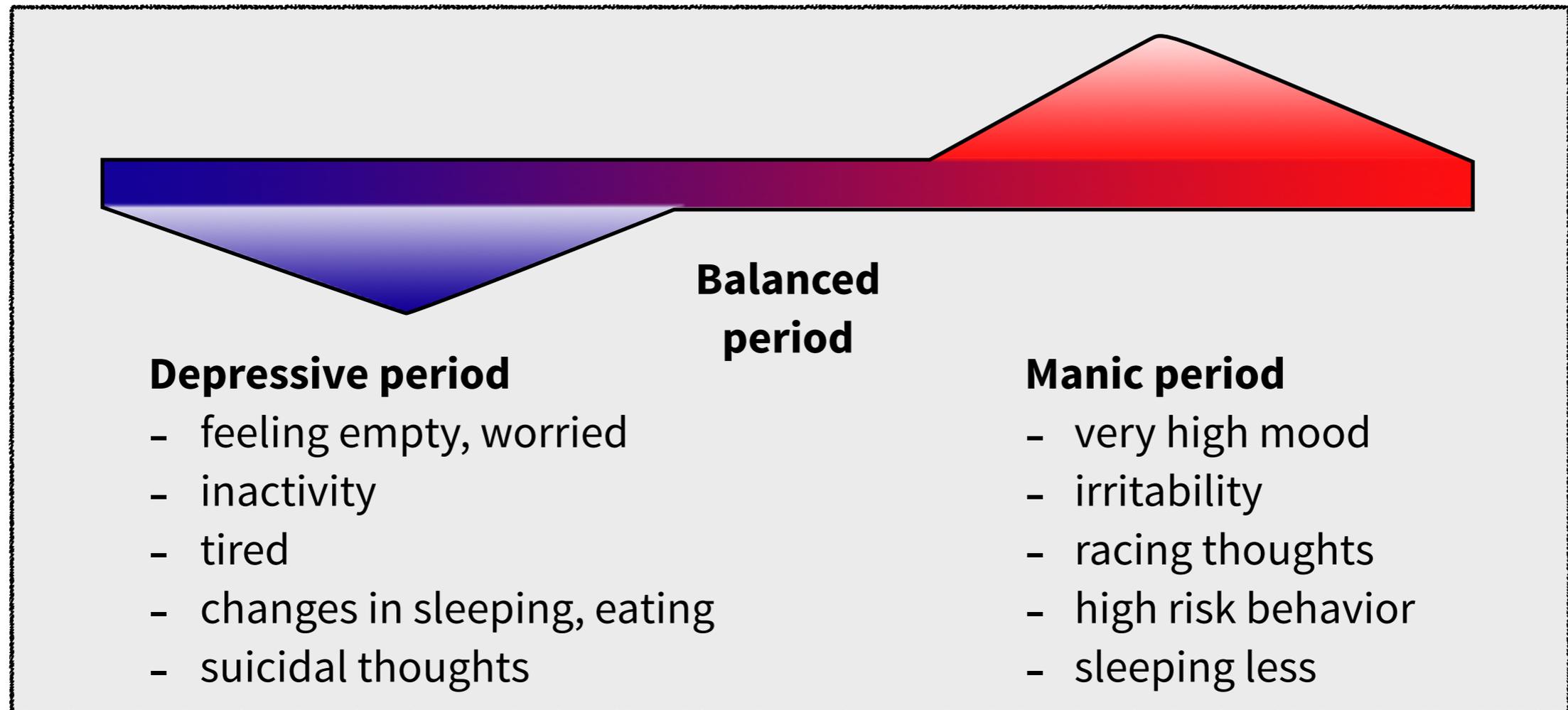
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- Insights into designing personal informatics tools for a mental health context

BACKGROUND

Bipolar Disorder (BD)

- One of **10** most debilitating illnesses worldwide
- **60 million** people; affects men and women equally
- **Chronic** — progressively worsens over a lifetime
- Permanent **neurological damage** with each relapse

Mood is central



STUDY

Research Questions

1. How and why do individuals with bipolar disorder engage in self-tracking?
2. How does the experience of bipolar disorder influence self-tracking practices?
3. What role does, or could, technology play in supporting the self-tracking needs of individuals with bipolar?

Participants & Procedure

- **N=10**
 - 5 females, 5 males
 - 25-64 years old
 - Confirmed diagnosis of BD, no active suicidal ideation
- Recruited through clinical collaborators
- Semi-structured qualitative interview & 2 surveys
 - \$50 for interview, \$25 per questionnaire
- Thematic analysis

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FINDINGS

Vignettes

- Personal stories that illustrate participants' lived experiences of BD and self-tracking
- Foreshadow thematic analysis
- Provide a holistic experiential context
- Pseudonyms used

Rachel

Background

- BD Type 1
- First episode ~25 yrs ago
- Masters degree
- Self-reports as highly structured and stable

Tracking history

- Started tracking post-diagnosis, on paper, shared with doctors
- Now only shares if problem
- Tracking helps her recognize patterns and make adjustments

Technology attitudes

- Self-declared tech enthusiast
- Has tried many apps, but aren't customizable enough
- Created her own custom digital tracking setup

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SRM II-5

Directions:

- Write the ideal target time you would like to do these daily activities.
- Record the time you actually did the activity each day.
- Record the people involved in the activity: 0 = Alone; 1 = Others present; 2 = Others actively involved; 3 = Others very stimulating

Date (week of): Feb 18 - 24 2013

Activity	Target Time	Sunday		Monday		Tuesday		Wednesday		Thursday		Friday		Saturday	
		Time	People	Time	People	Time	People	Time	People	Time	People	Time	People	Time	People
Out of bed	6:30am	8:00am	0	6:15am	0	8:00am	0	6:45am	0	7:00am	0	8:07am	0	7:00am	0
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Start work/school/volunteer/family care	8:40am	10:00am	2	8:10am	2	11:40am	1	8:30am	2	11:40am	1	9:00am	0	7:00pm	0
Dinner	5:00pm	6:00pm	0	7:00pm	0	5:40pm	0	9:30pm	0	5:30pm	0	5:30pm	0	6:00pm	0
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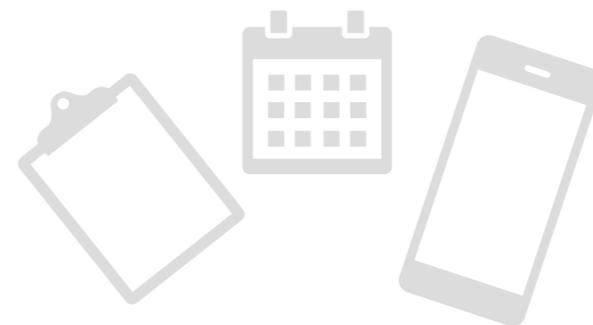
All participants self-track



Most elaborate and intense post-diagnosis



Typically clinician-initiated



Independent practices adopted

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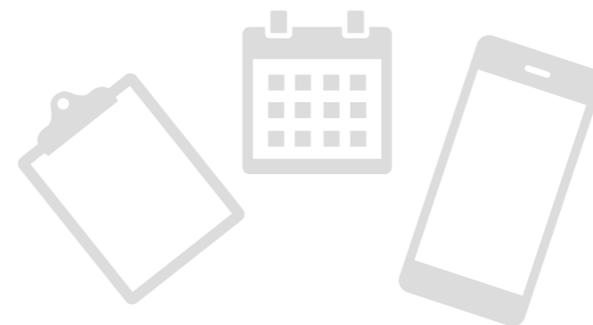
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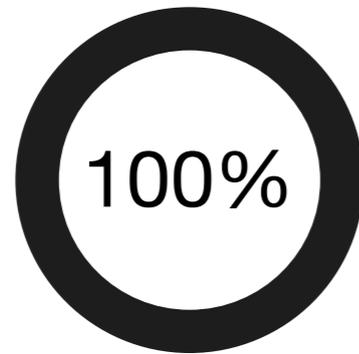


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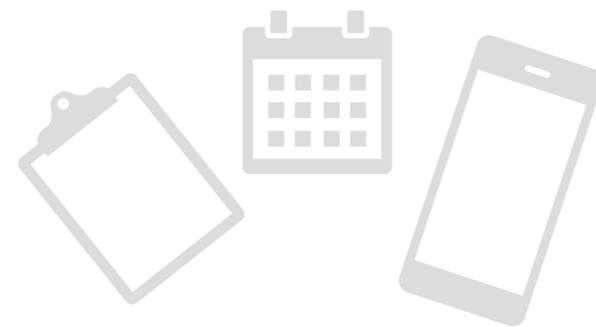
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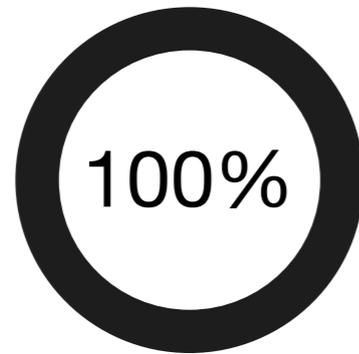


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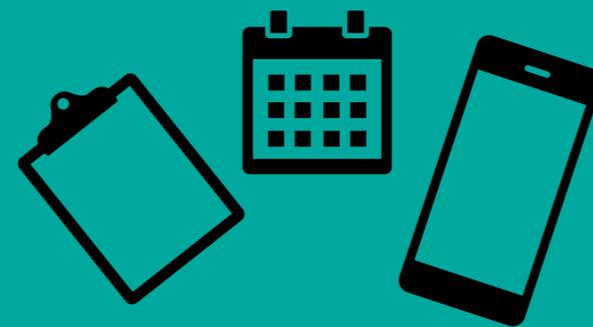
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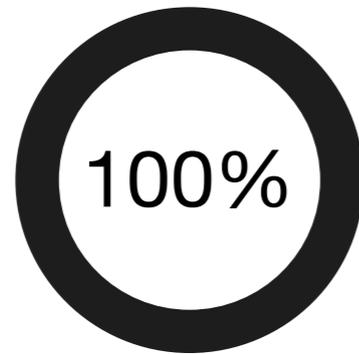


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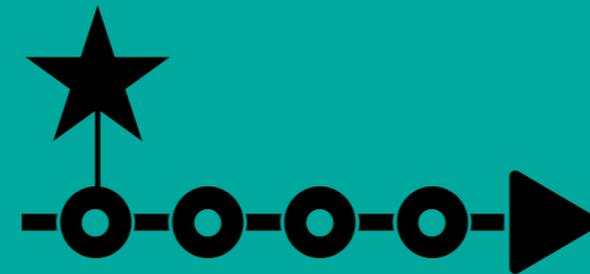


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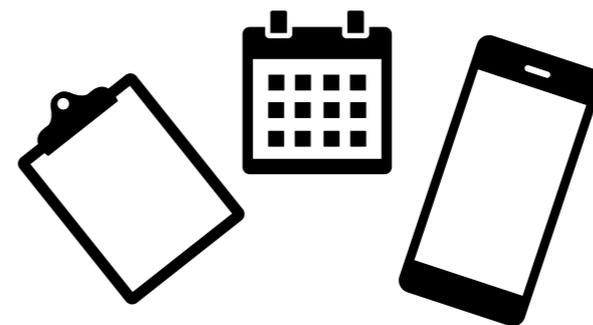
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Normalcy &
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Mindfulness &
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Countering
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Identifying patterns &
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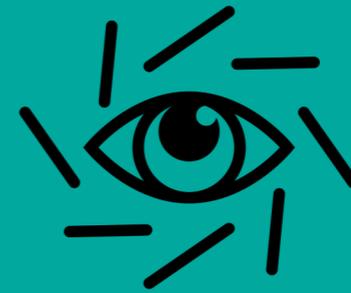


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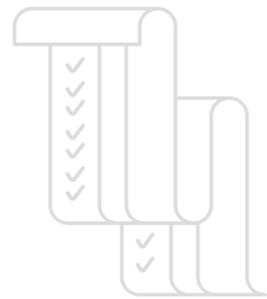
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How does the experience of BD influence self-tracking practices?



Multitude of tracking targets



Risk of hyper self-scrutiny

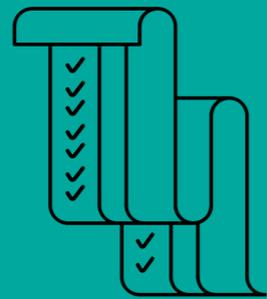


Reliability of assessment



Consistent reporting & reflection

How does the experience of BD influence self-tracking practices?



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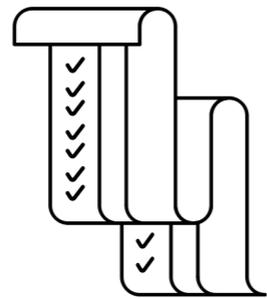


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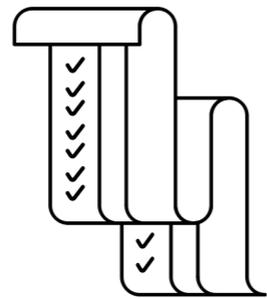


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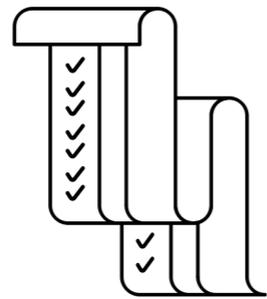


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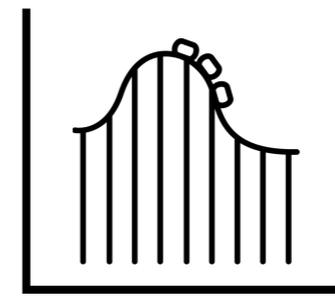
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Therapeutic Benefit

- Accountability to digital “companion”
- Automated reminders can improve adherence, prompt reflection & action
- Passive sensing perceived as “objective witness”
- Reduces burden
- Delivery of positive feedback highly motivating

Psychological Risk

- Passive approaches can hamper agency, awareness
- Privacy concerns
- Accuracy disclaimers needed
- Usage can exacerbate and trigger symptoms
- Social stigma, demoralization
- Negative or judgmental feedback can provoke distress and abandonment

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DESIGN CONSIDERATIONS

QS in a Mental Health Context

Aiming for
Unremarkable



Framing feedback
to celebrate stability

Finding vs.
Quantifying the Self

- Confusion over “true” self due to contradictory experiences of self across mood states
- Self-acceptance
- Stabilizing not just behavior but identity

Aiding self-construction
and acceptance

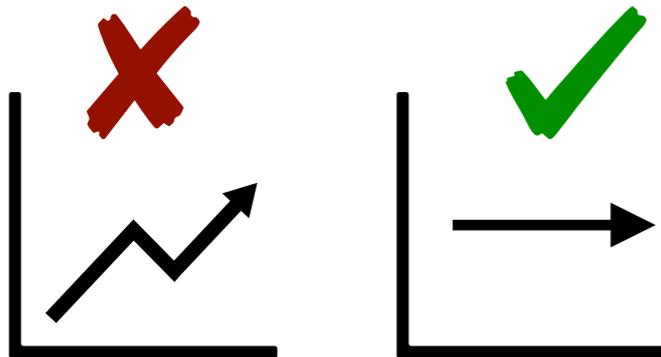
Staging Model
of BD

- Pre-diagnosis
- Post-diagnosis
- Maintenance
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- Stabilizing not just behavior but identity

Aiding self-construction
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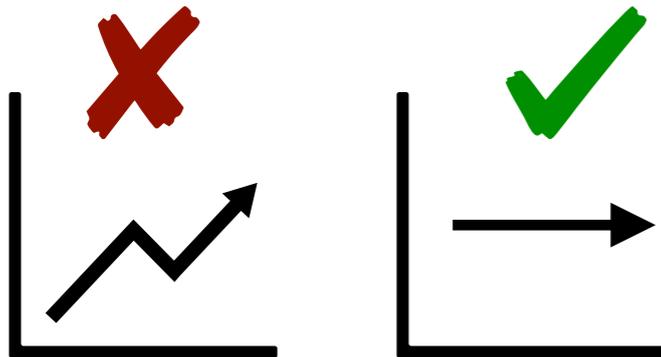
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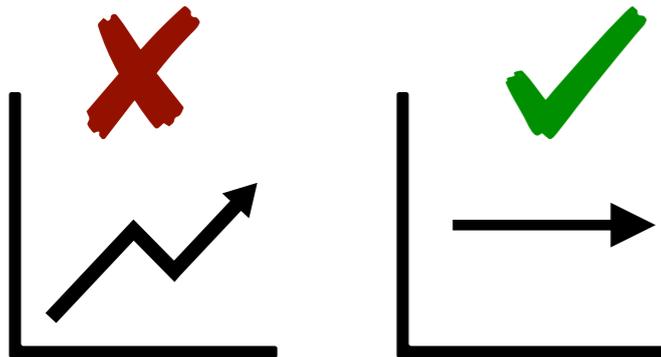
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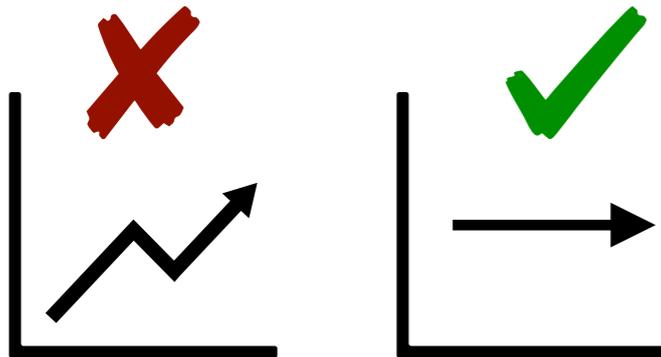
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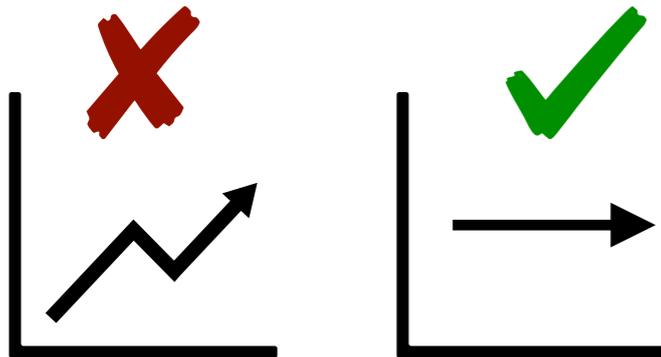
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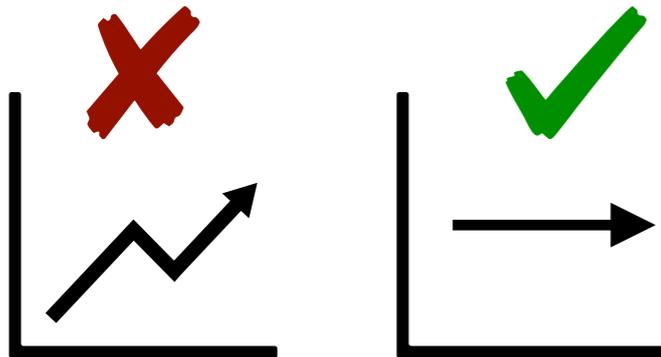
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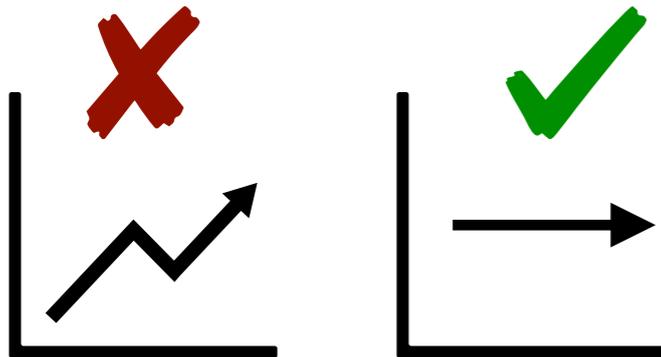
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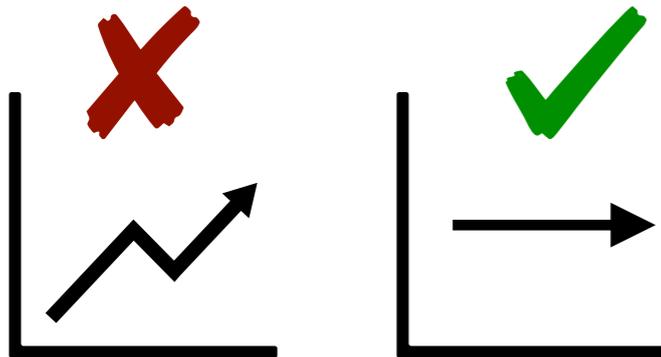
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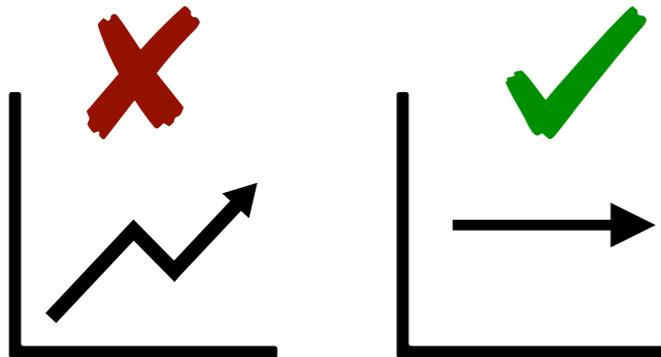
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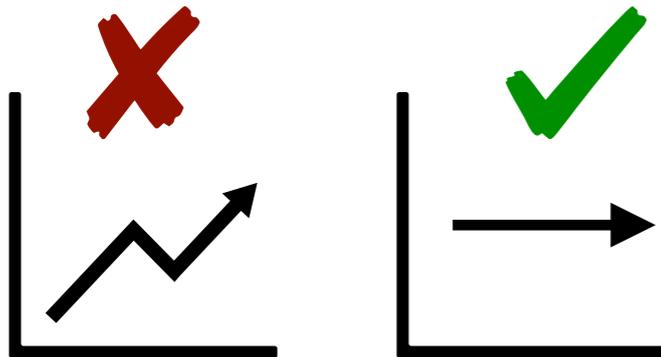
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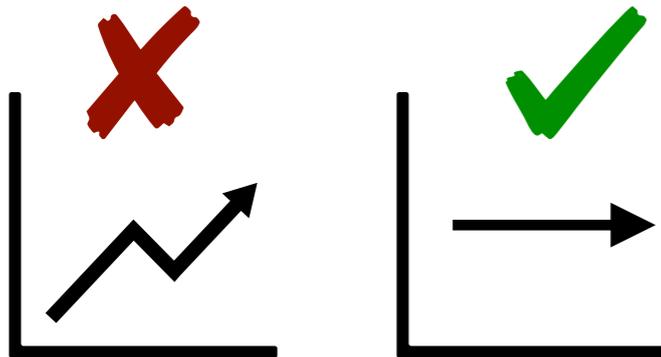
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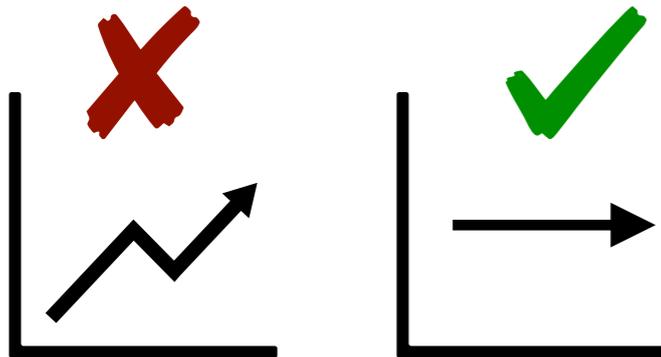
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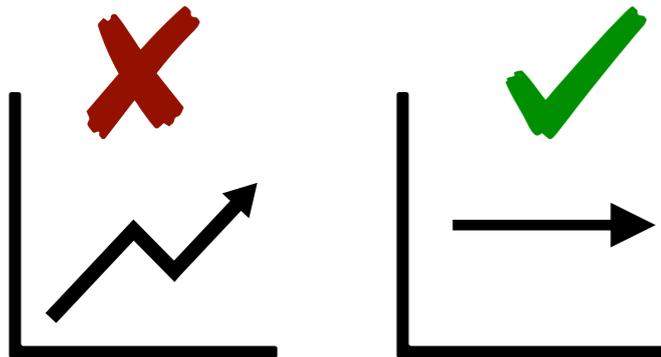
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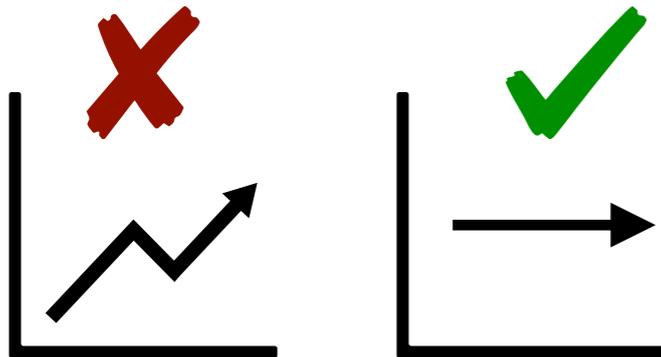
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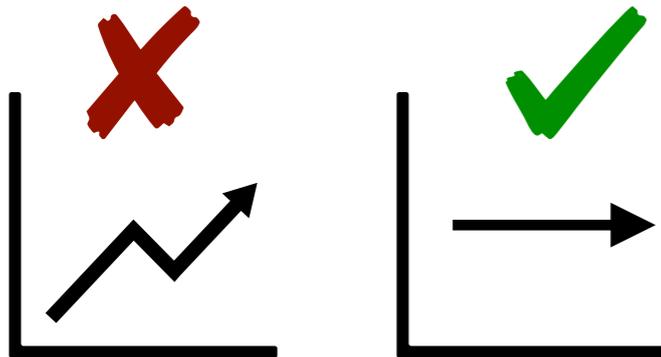
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