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Tracking development at home, in therapy and at school

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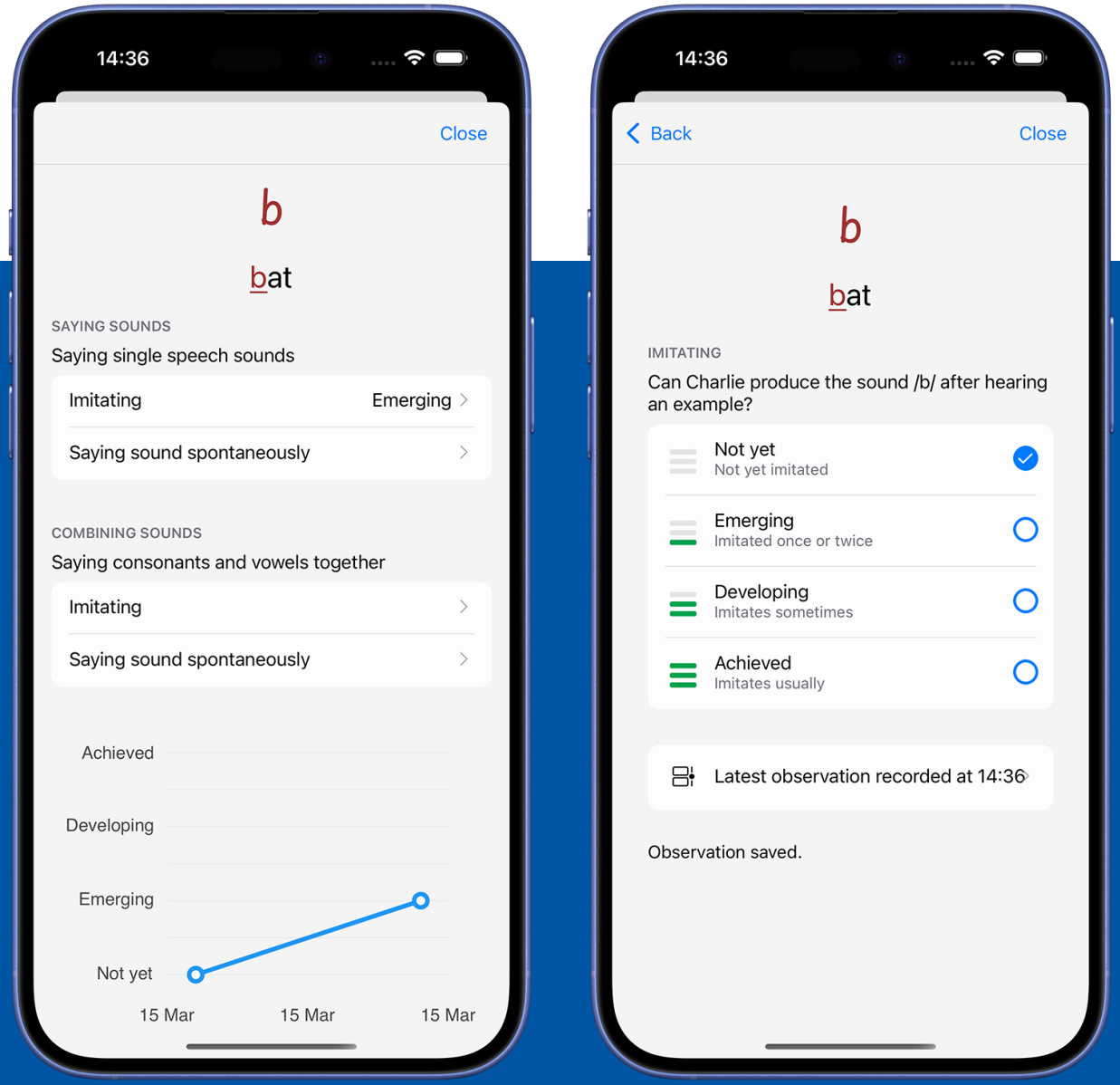
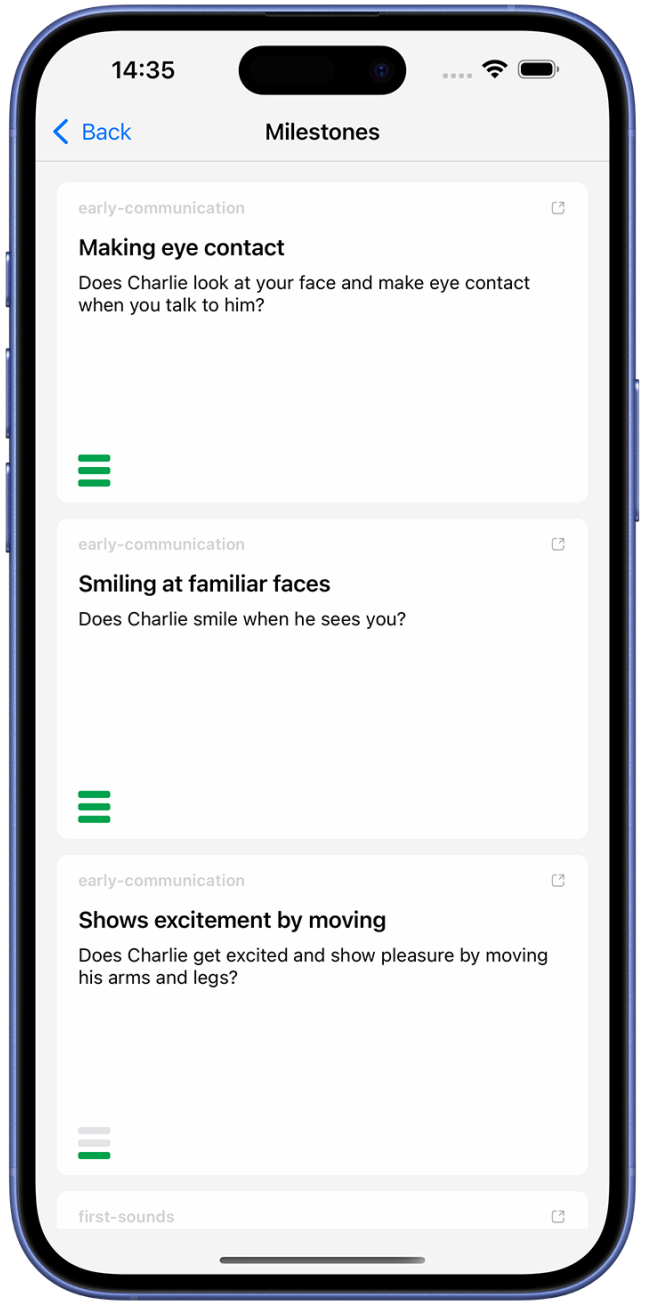
Down Syndrome Education International

Down Syndrome Education USA



From observations to advice

- We all observe our children, our clients, our students and our study participants
- Advice and support for families and educators relies on observations (usually theirs)
- By making it easy to record progress and share observations we can deliver more accurate and more timely advice
- By collecting observations of many children over many years we can advance our understanding of their development (and further improve advice)



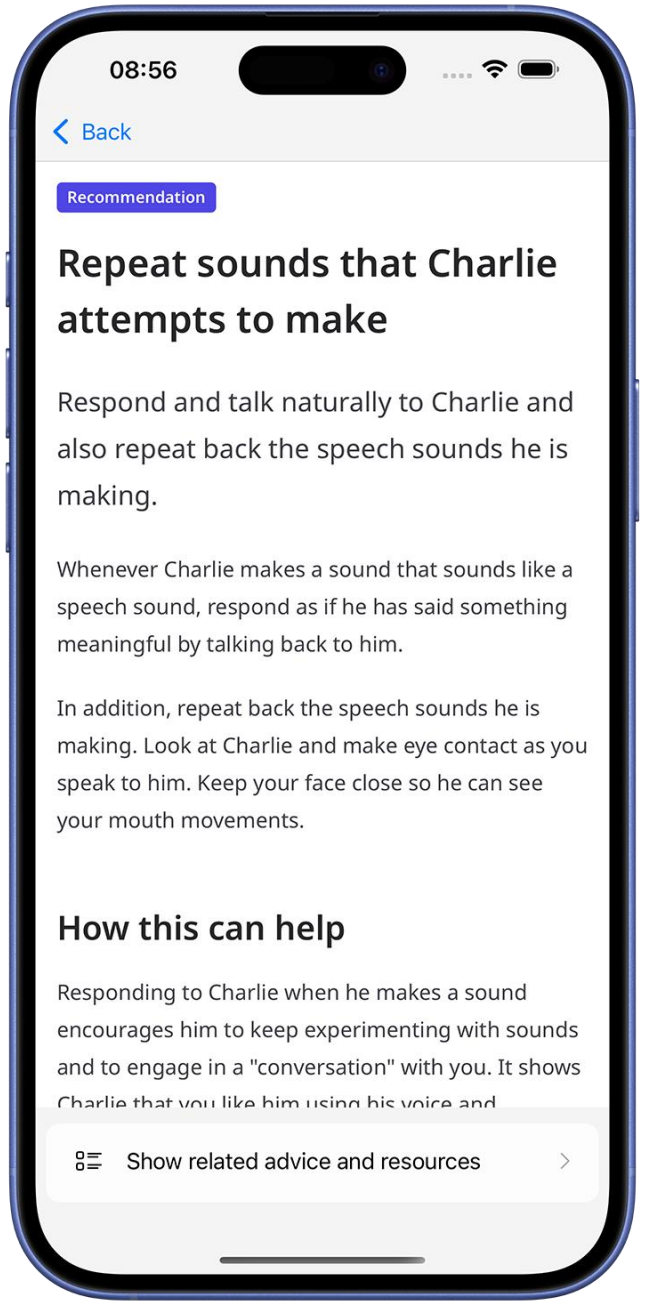
From observations to advice

We have built systems to:

- **collect observations** across a variety of development, speech, language and literacy measures
- analyse observations to monitor progress and to **provide data-driven, personalised advice**
- **share large datasets** with the research community

https://www.down-syndrome.org/papers/2024/research-practice/

https://community.down-syndrome.org/t/an-update-on-our-planned-progress-tracking-and-advice-services/98



Progress tracking apps

Over the past 11 months, we have focused on developing user interfaces to these systems…

Three progress tracking apps:

- **My Child's Progress** – to support families
- **My Clients' Progress** – to support speech and language therapists, early years professionals and organisations
- **My Students' Progress** – to support teachers and other education professionals working with school-aged children

Connected teaching apps

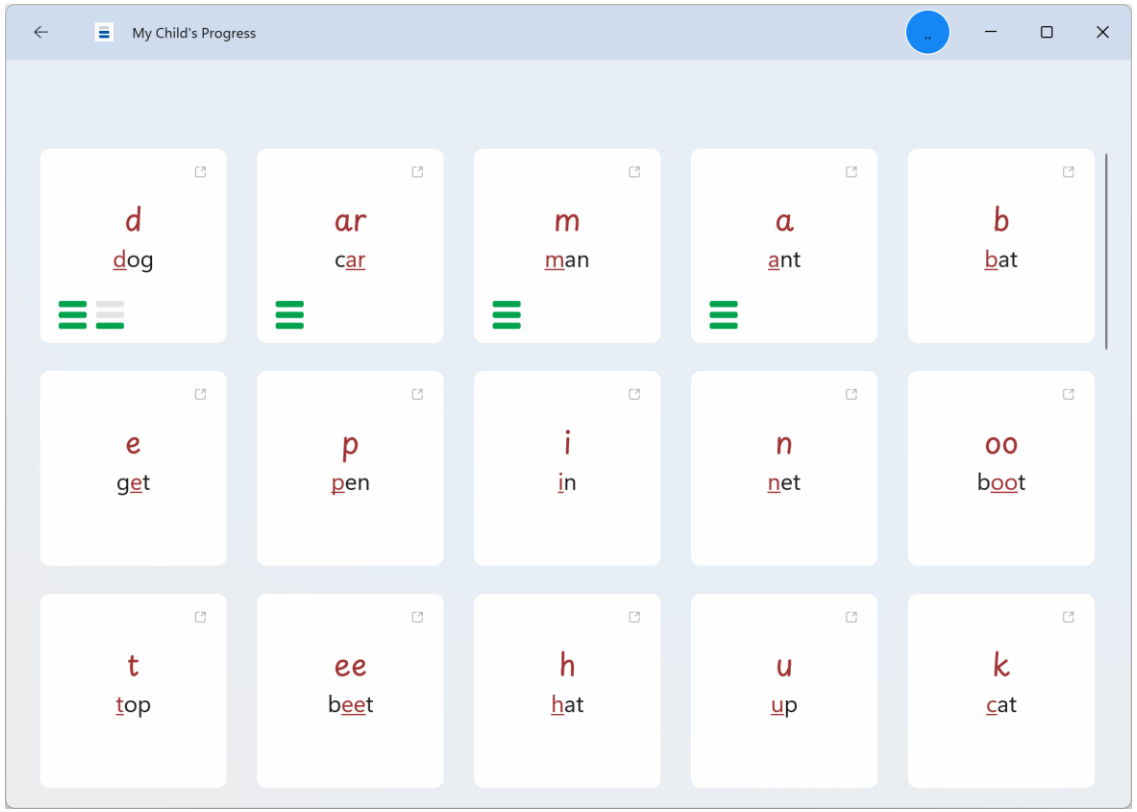
Three teaching apps:

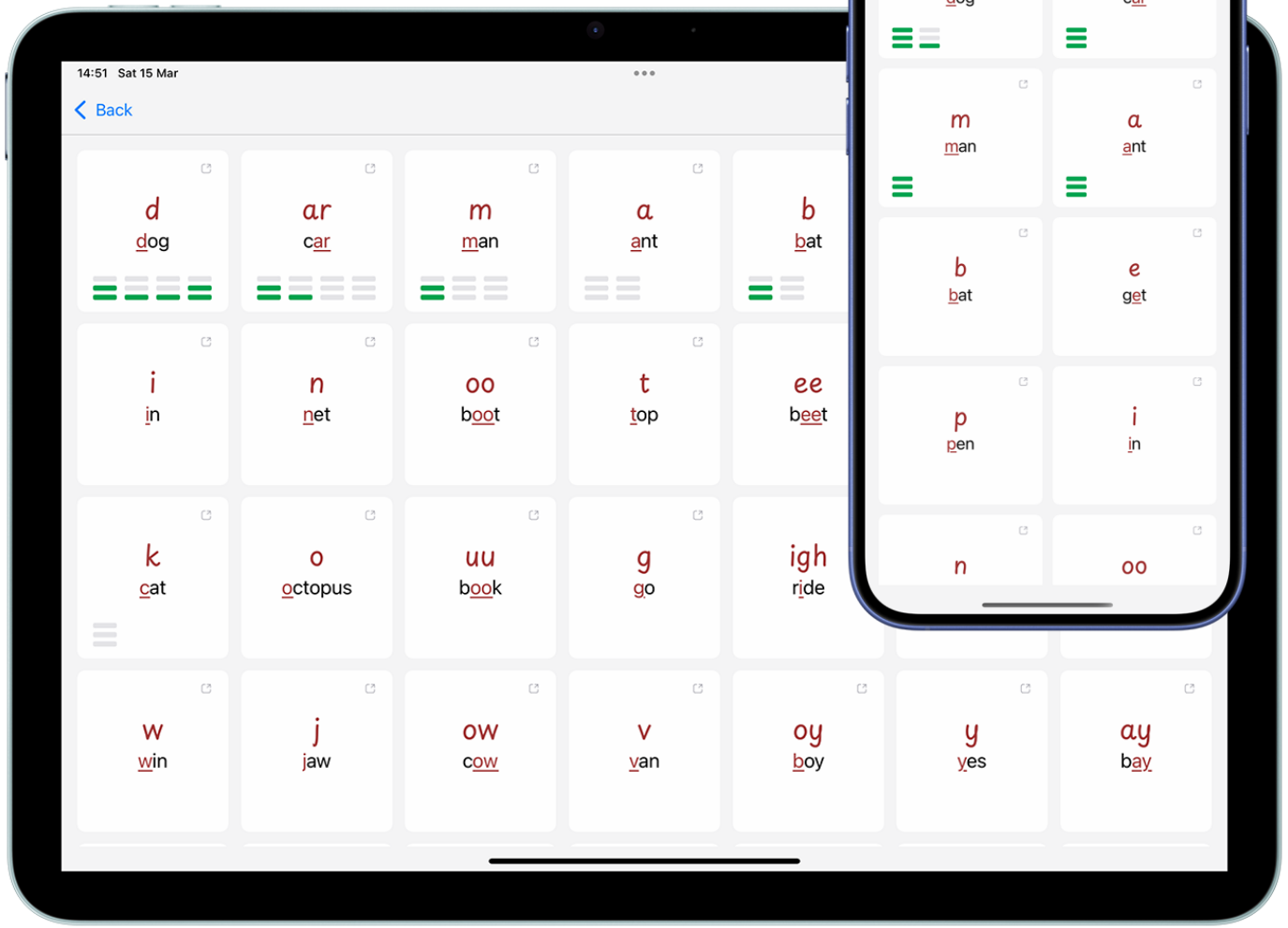
- **See and Learn** – a unified app bringing together the See and Learn speech, language, reading and numeracy teaching activities
- **My Words** – personal vocabulary/picture library with matching and selecting activities
- **My Stories** – personal story books

- Each connects with observations systems to automate activity/achievement recording

Supporting multiple platforms/devices

- Windows, Mac, iPads, iPhones, Android tablets, phones, desktop/laptop

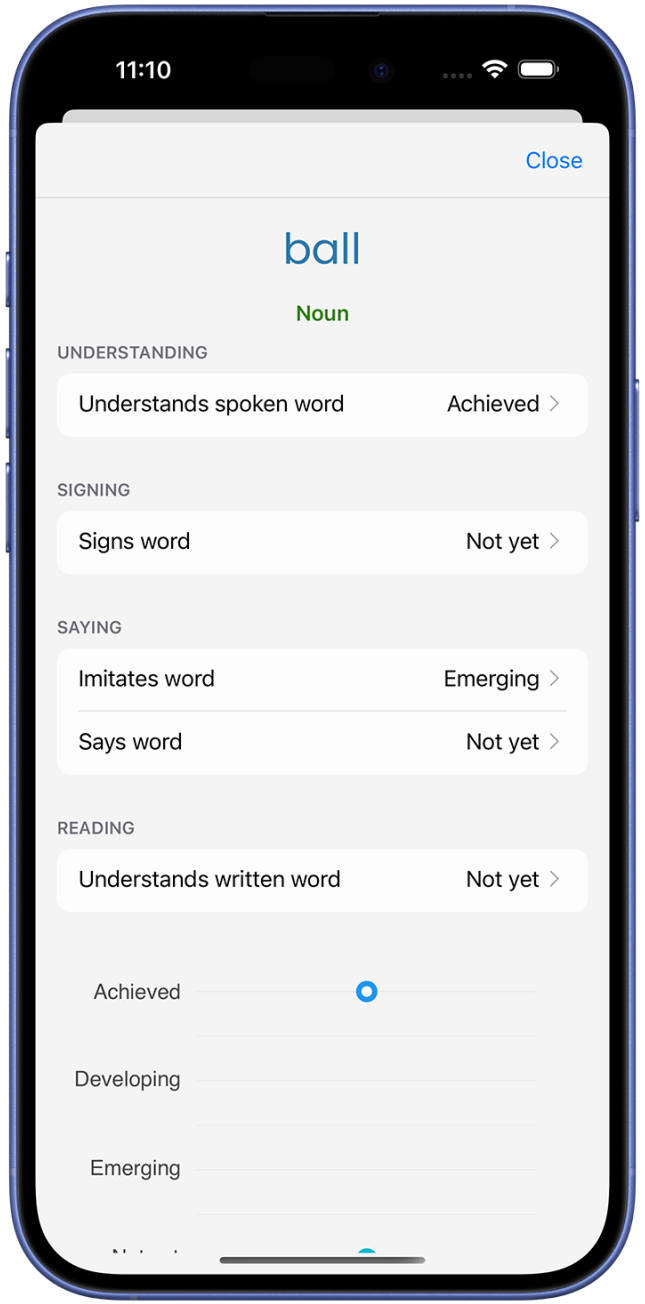




Observations

Tracking progress across a range of measures:

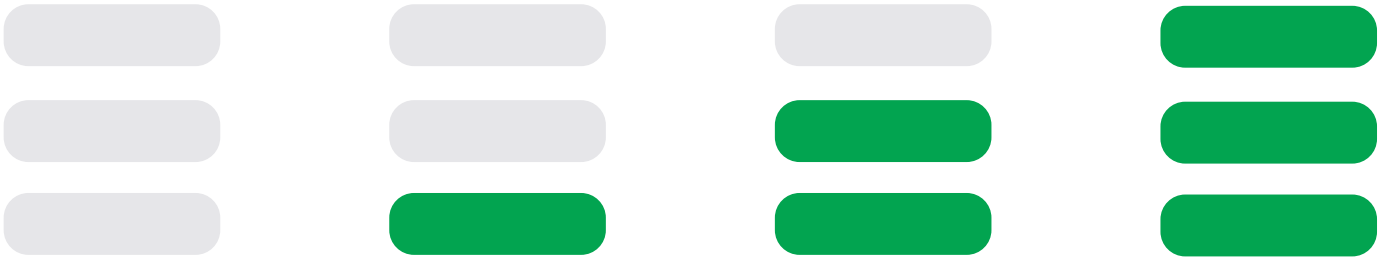
- **developmental milestones** – markers for social/emotional, communication, language, motor, reading and number development
- **speech measures** – single phoneme and consonant-vowel imitation and independent production
- **language measures** – single word comprehension, signing, and spoken imitation and independent production – also phrases and sentences comprehension
- **reading measures** – single words, phrases and sentences

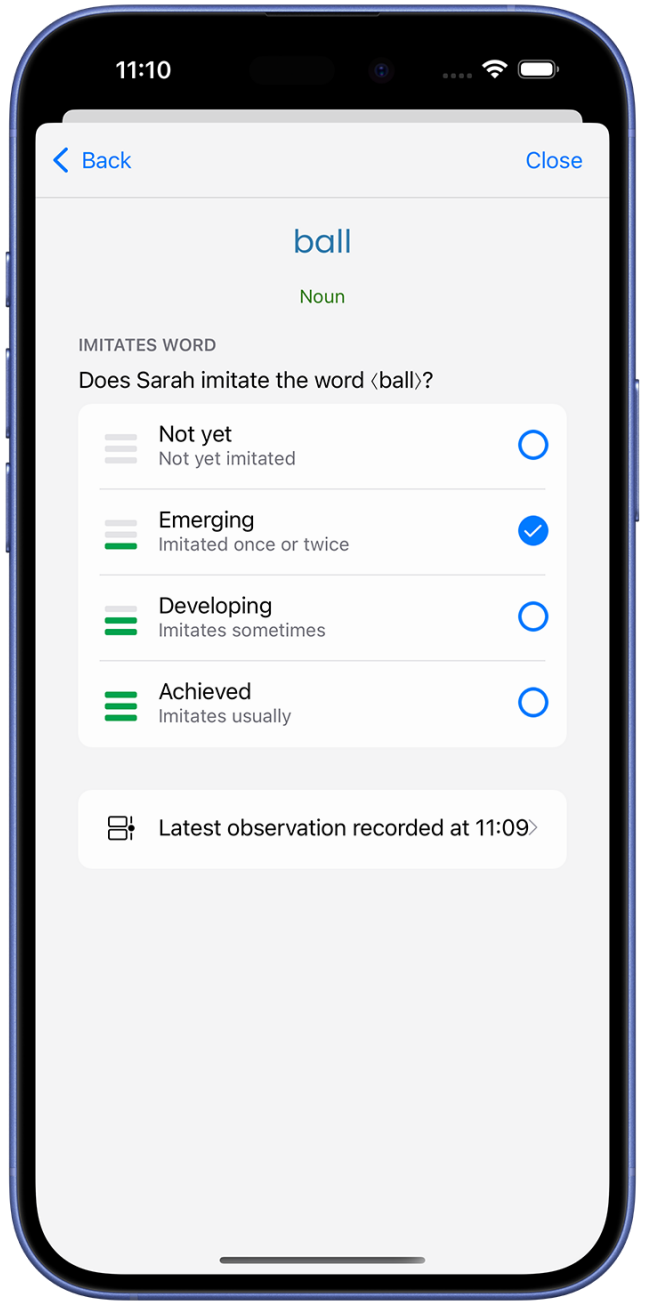


Observations

Celebrating small steps:

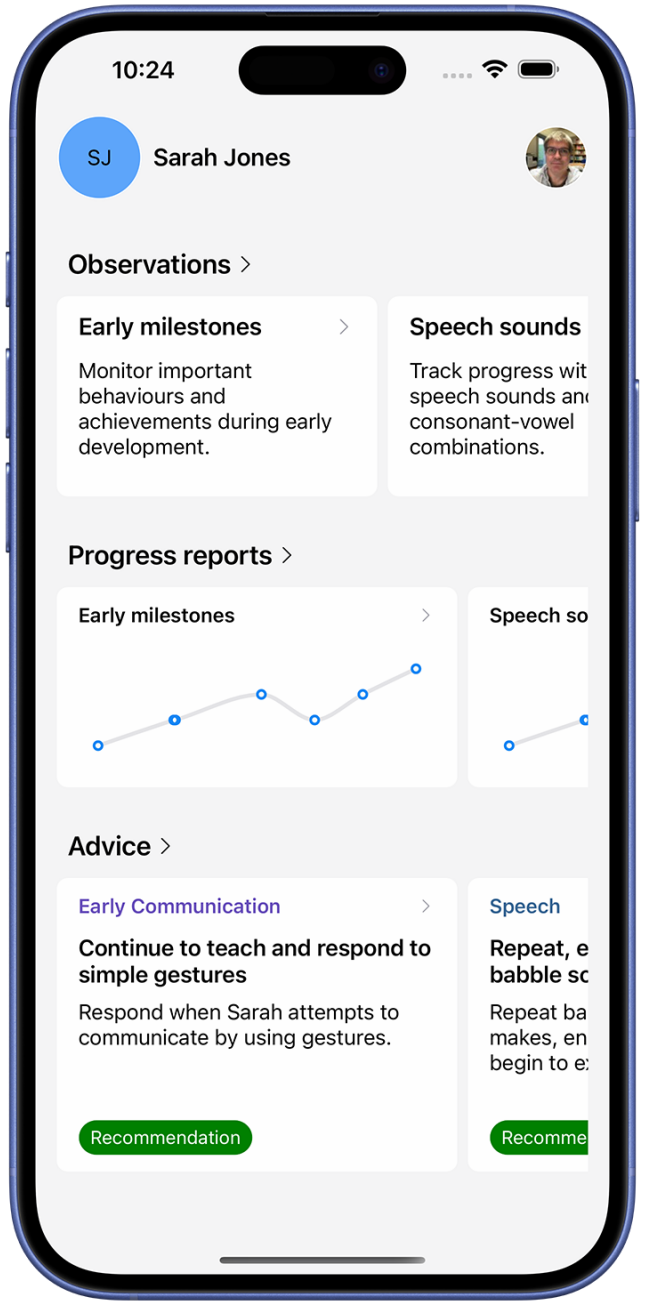
- New skills can take time to become established
- We record progression as skills learned rather than a simple yes/no
- Add past observations
- Add annotations (notes, recordings, photographs)





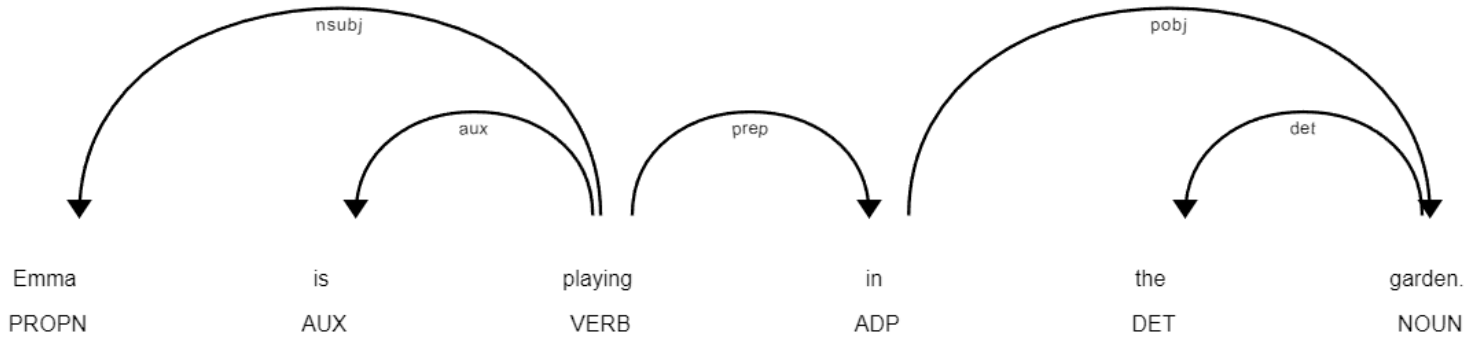
Monitoring progress

- Chart progress on single and multiple related measures
- Progress reports summarising progress across an area/aspect of development
- Progress reports for multiple children (My Client/My Student)
- Progress reports link to relevant guidance and advice

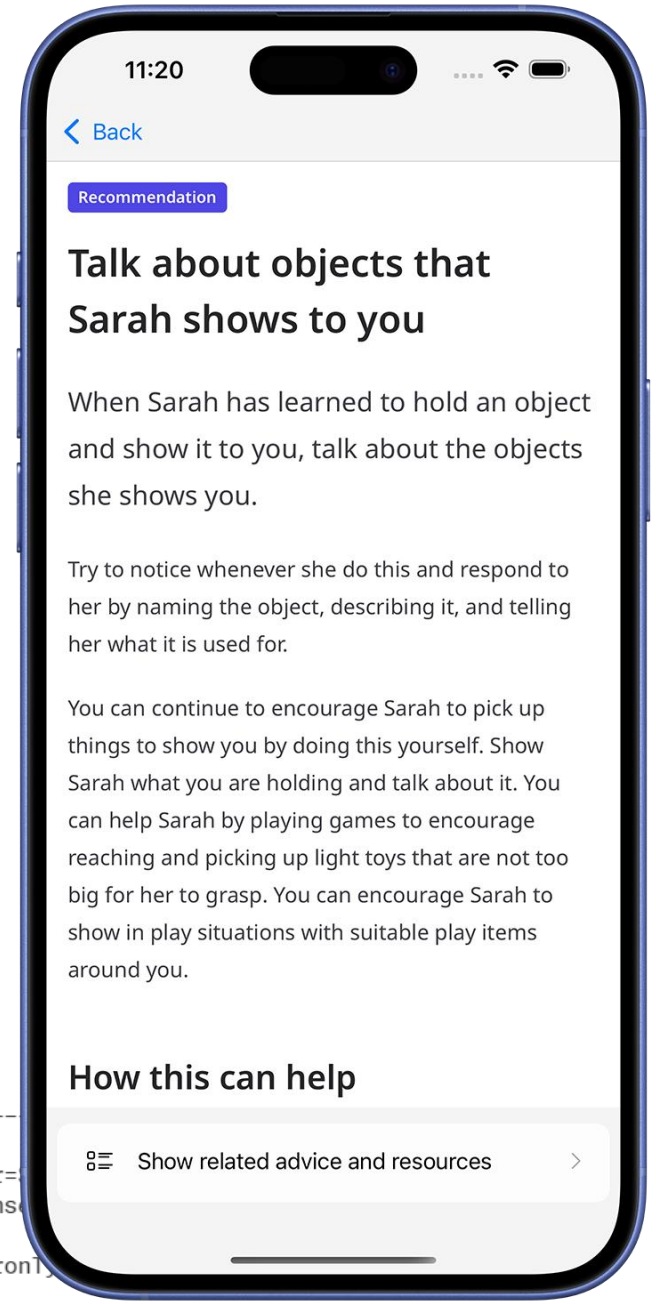


Personalised advice

- Advice is based on observations recorded
- Advice generation is informed by a rich model of speech and language, mapping words, sentences and speech sounds

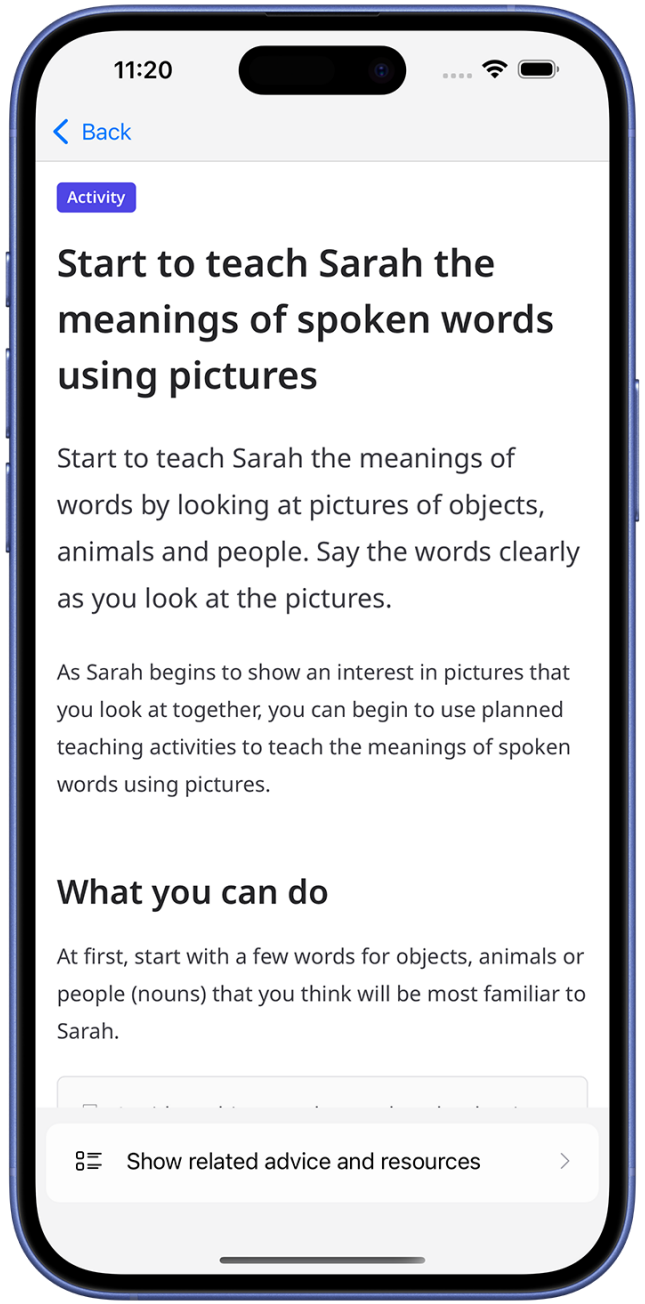


Index	Token	Lemma	POS	Tag	Dep	Head	Left	Right	Features
0	Emma	Emma	PROPN	NNP	nsubj	playing	Emma	Emma	Number=Sing
1	is	be	AUX	VBZ	aux	playing	is	is	Mood=Ind|Number=
2	playing	play	VERB	VBG	ROOT	playing	Emma	.	Aspect=Prog|Tens
3	in	in	ADP	IN	prep	playing	in	garden	
4	the	the	DET	DT	det	garden	the	the	Definite=Def|PronT
5	garden	garden	NOUN	NN	pobj	in	the	garden	Number=Sing
6	.	.	PUNCT	.	punct	playing	.	.	PunctType=Peri



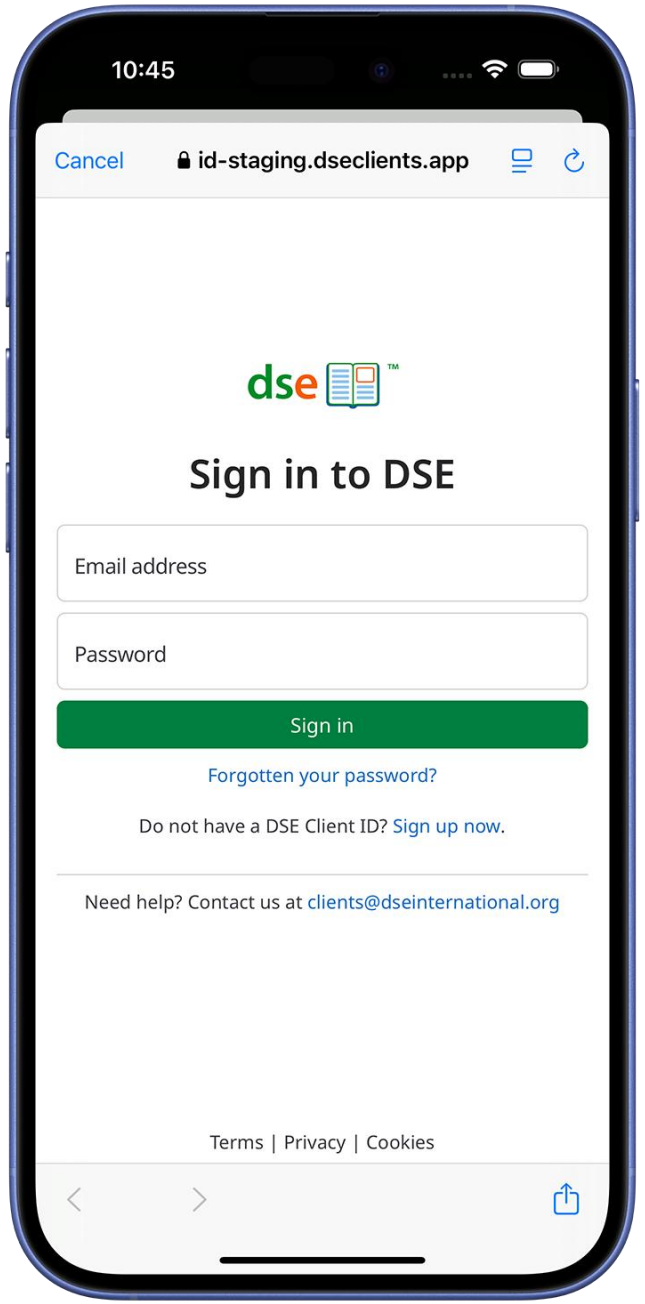
Personalised advice

- **Advice generation is deterministic**
- We do use deep learning models to help build our speech and language model
- We **do not** use language models to generate advice
- We define explicit rules for each advice item
- We are investigating using language models to support natural language user interactions (but not to ‘reason’ about advice)



Sharing and collaboration

- **Share progress reports** - recipient does not require app – can view on a web site
- **Share access to tracker** – within family, between parents and therapists and teachers, within school
- **Fine-grained access control system** – share read-only access or parts of tracker data



Observation data

An observation records a value relating to a measure at a point in time

- Recorded in sets of one or more observation, together with information about the source and the observer
- May be supplemented with annotations


```
{
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    "src": "org.mychildsprogress.app://dse.progress.mychild.nativeapp/2025.20.67.18680/records.speech
    "obs": [
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    "_attachments": "attachments/",
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}
```


subject (child)
observer
source

time
measure id
parameter (optional, number/text)
value (ordinal, count, ratio…)

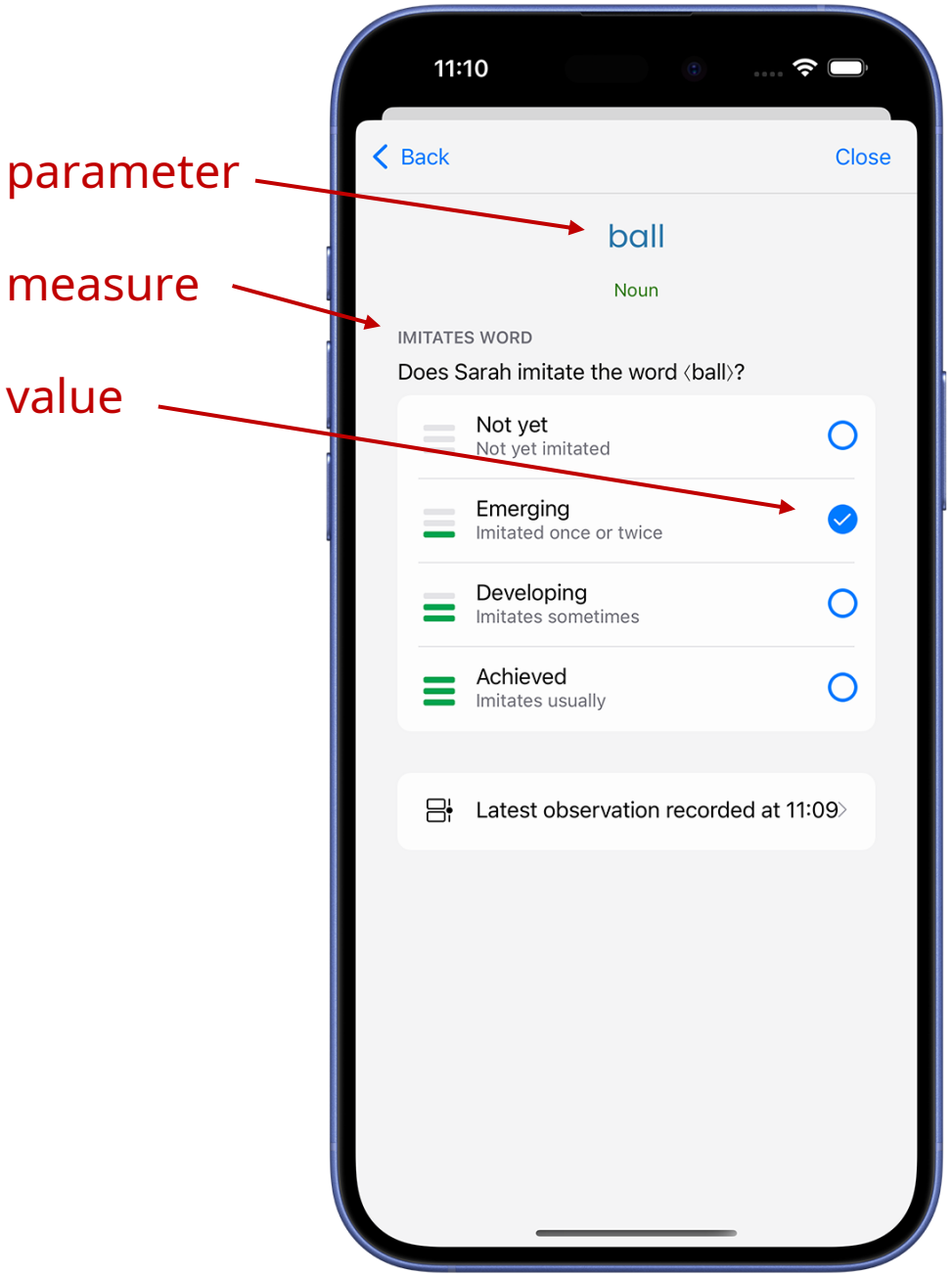
Observations data

Simple measure:

- “{subject} smiles when she sees a familiar face”
- [not yet/emerging/developing/achieved]

Parameterised measure:

- “{subject} imitates a speech sound”
- [not yet/emerging/developing/achieved]
- “/ar/”



Observations data

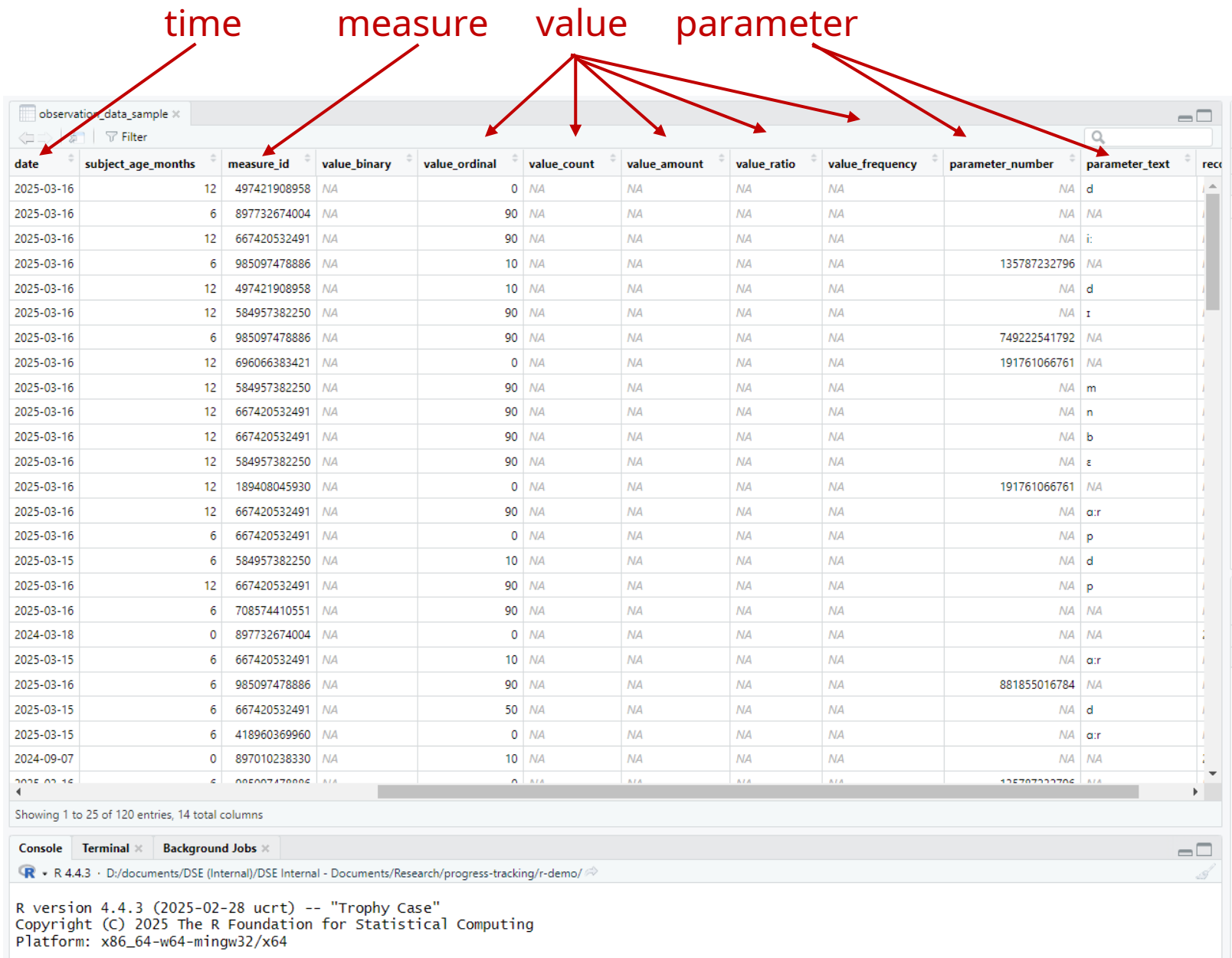
- **Operational data** (trackers, subjects, observers, observation sets) stored in globally replicated databases (currently in three locations)

- Reduced latency for users
- Redundancy and fail-over

- Changes to operational data are processed to create **analytical data**…

Observations data

- **Analytics data** stored in separate database (also replicated)
- Better suited to efficient query processing
- Data is largely anonymised in the analytics database
- Analytics database can evolve over time with additional views, indexes, data structures, independently of operational database

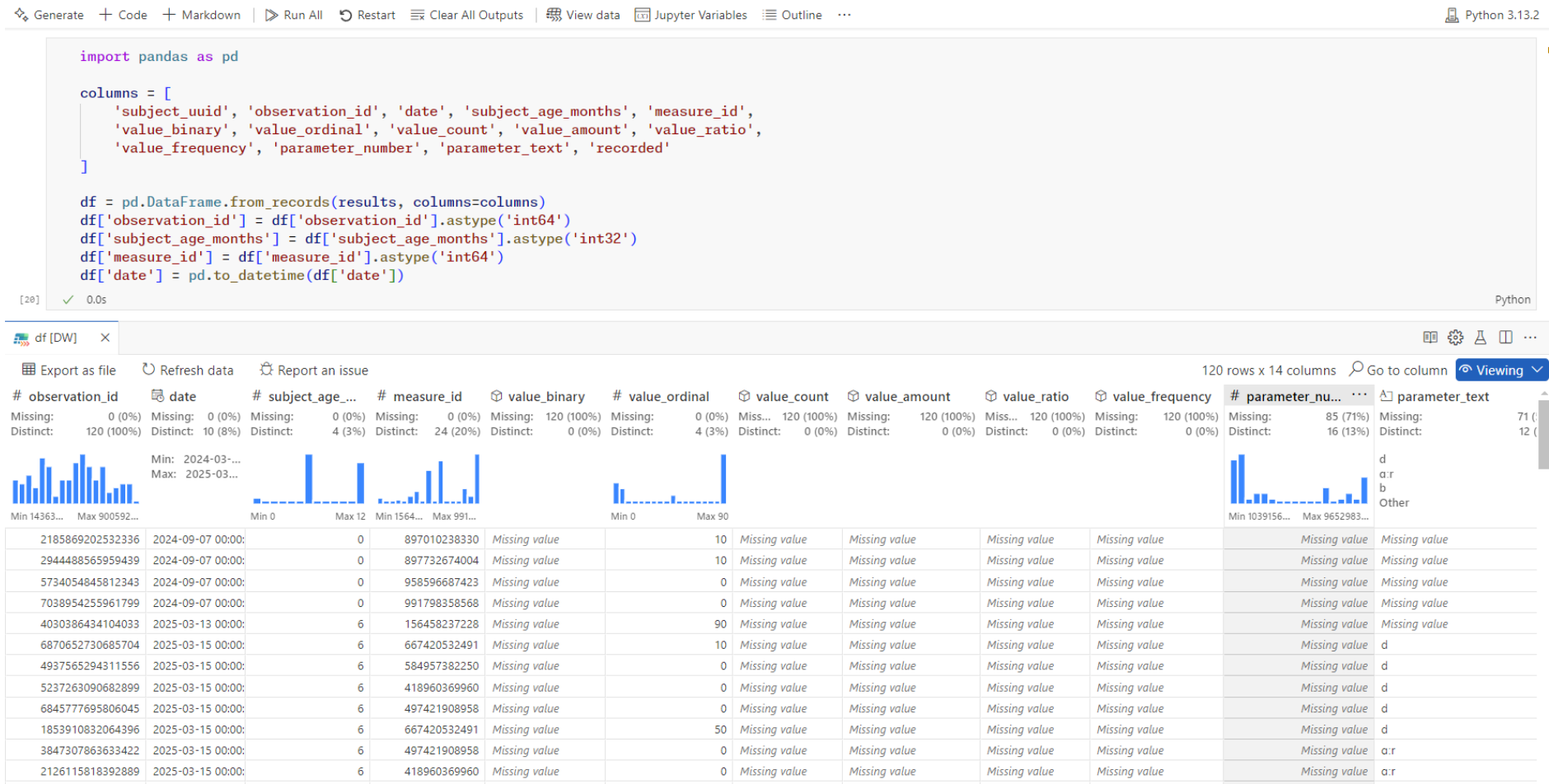


Observations data

- Can query and analyse observations data using common statistical analysis tools

- We expect to make fully anonymised data sets available

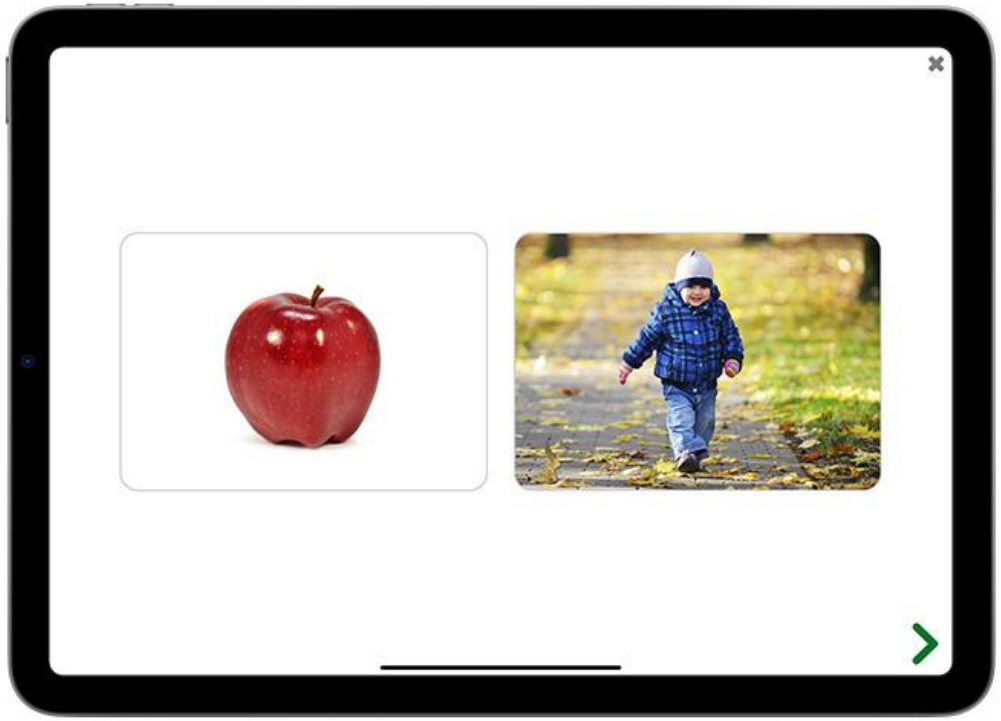
- Connecting with R and Python tools



Extensibility and partnerships

- We have built the apps and the record keeping systems to be extensible

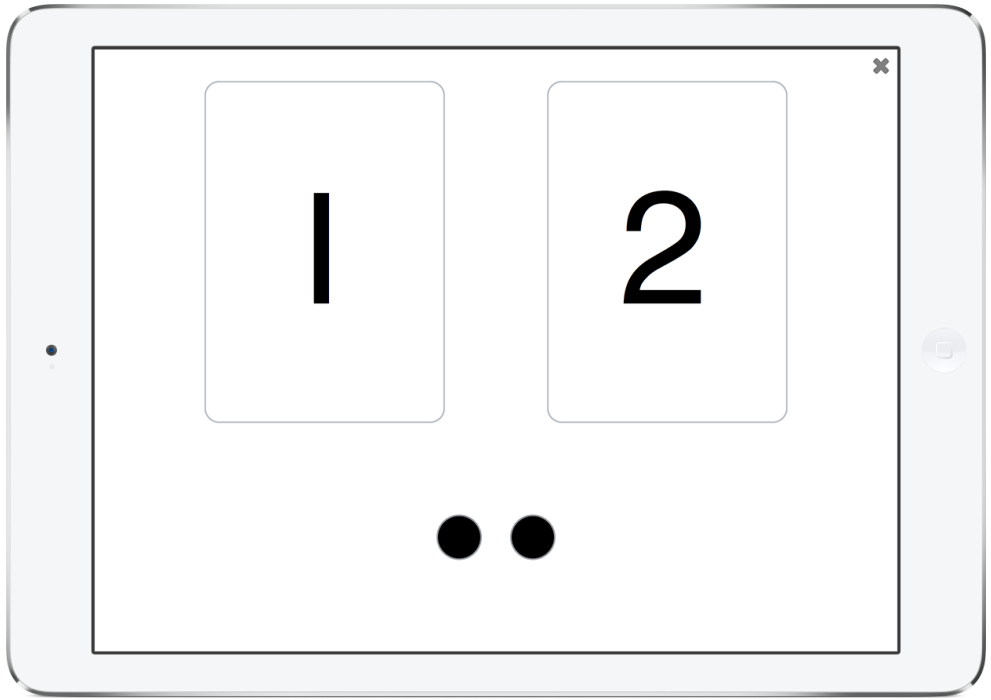
- Research partners can integrate observation collection with their own web sites or apps – for example, to support a project with a specific set of measures or recording device



Extensibility and partnerships

- We can also build in additional observations into the existing apps and make them available to study participants

- By linking with our records systems, researchers can collect custom measures alongside existing measures – providing additional data and avoiding duplication for study participants

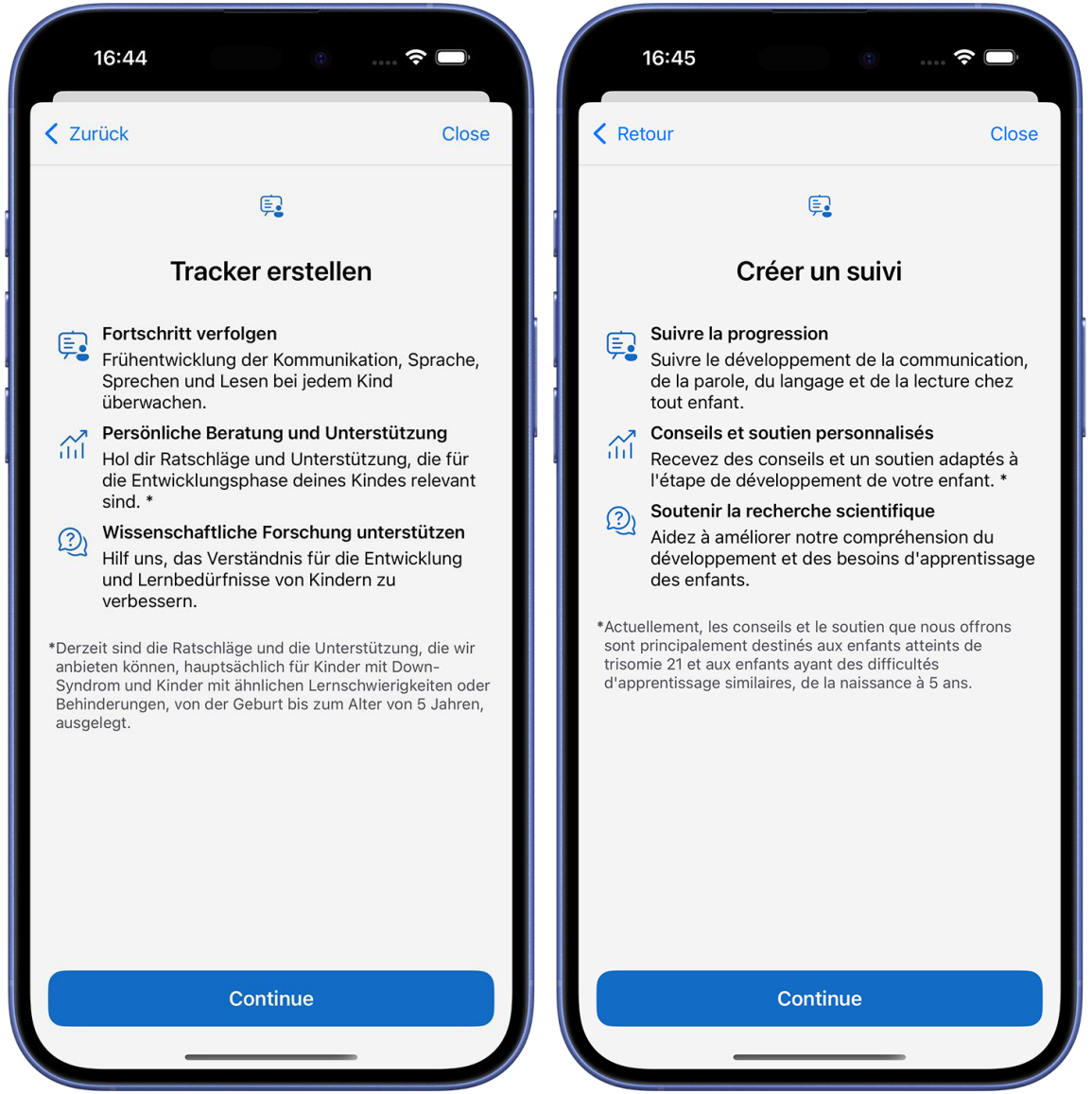


Extensibility and partnerships

Translations and adaptations

We are beginning to look for partners interested in extending the record keeping systems and apps to better support families and professionals in different countries and multiple languages

- Translating and adapting our speech and language model
- Translating and adapting advice and guidance
- Linking advice and guidance to additional local resources



Previews and release dates

- We expect to start trialling previews of My Child's Progress with families in the next several weeks (Windows and iOS at first)
- Depending on feedback, we hope to begin to share early previews of My Client's Progress with speech and language therapists and groups providing direct services by mid-summer
- Previews of My Student's Progress will likely begin later in the year

Previews and release dates

- We hope are first full release of My Child's Progress will be available for families in the autumn
- We may begin with the 0–3 age group and extend from there
- We are also working towards releasing the new unified See and Learn app (that connects with the record systems) in the autumn

And then…

Future directions:

- Different input modalities – audio, video
- Can we train models to (say) analyse speech and provide clinically-appropriate recommendations?
- Can we model interactions between measures in multiple domains over time to better inform our understanding (and generate better-informed advice)?

- To what extent can we accelerate the research–practice loop?

How to get involved

Announcements and updates

- Mailing list (https://www.down-syndrome.org/mail/subscribe)
- https://www.down-syndrome.org/progress/
- https://www.down-syndrome.org/news/
- https://bsky.app/profile/dseinternational.bsky.social

Feedback, thoughts, questions

- https://community.down-syndrome.org/c/progress/23