



Consumer e-health

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Support systems for consumers

- Early forms: home library reference databases, body atlases, pamphlets of patient advice
- 1990s: online content and decision support aids for healthcare consumers started to emerge
- Now: e-health, social and Web 2.0 technologies

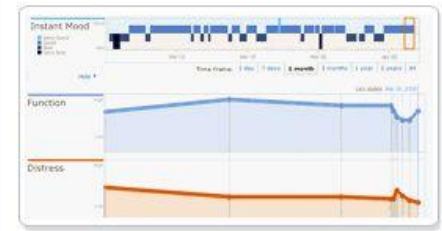


The PatientsLikeMe Mood Conditions Community

[Home](#) > [Mood Conditions Community](#)

Whether you're depressed, bipolar, anxious, obsessive-compulsive, or simply want to monitor your mood fluctuations, this is the online community for you. By sharing your symptoms, treatments and mood charts, you can gain insight into what affects your mood while helping others learn from your experiences. Create a profile today to begin taking control of your health. Imagine knowing every medication, supplement, or device used to treat your disease. Imagine knowing what treatments work for people just like you — and having the ability to easily connect with those people. That's what makes PatientsLikeMe different. Patients share their treatments and outcomes not just to help themselves, but to help others. Become part of making a difference for everyone with mood conditions today.

An Innovative Approach Designed Specifically for Mood Conditions



Relevant Outcomes
Answer simple questions every week about your Function, Distress, External Stress, Life Activities, and Symptoms to create your Mood Map—a graphic representation of what factors affect your mood.



Relevant Treatments
Enter your treatments and share your regimen with others. Stay abreast of the latest treatment options for your condition through our Treatment Reports.



Our Mood Conditions Community



376 **Patient updates this week**
Using PatientsLikeMe, people with mood conditions share detailed information about their symptoms, treatments, overall progress, and more.

637 **New patients this month**
PatientsLikeMe members can find other patients like them experiencing similar symptoms and taking the same treatments.

5126 **Mood Conditions patients in our community**
Today, 5126 people with mood conditions are learning from each other on PatientsLikeMe. [See more mood conditions patients...](#)

Top mood conditions Treatments

- Individual Therapy (804 patients)
- Bupropion (305 patients)
- Clonazepam (255 patients)
- Lamotrigine (250 patients)
- Fluoxetine (210 patients)
- Escitalopram (200 patients)
- Venlafaxine (195 patients)
- Sertraline (184 patients)
- Pets (166 patients)
- Omega 3 (155 patients)

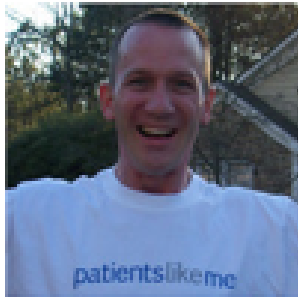
[See all 1242 treatments...](#)

Top mood conditions Symptoms

- Problems concentrating (2033 patients)
- Muscle tension (1745 patients)
- Headaches (1589 patients)
- Back pain (1424 patients)
- Stomach pain (1144 patients)
- Dizziness (1070 patients)
- Nausea (1018 patients)
- Hyperventilation (557 patients)
- Fatigue (455 patients)
- Anxiety (408 patients)


[See all 721 symptoms...](#)

SmoothS's PatientsLikeMe ALS Profile



SmoothS

Male, 39 years
Marietta, GA


 ALS: 2 yrs


Member since: 10/06
Last updated: 03/19/08

Diagnosis Summary

Onset: Arms
First symptom: 09/05
Diagnosis: 10/06

Forum Activity

958 posts  1182 helpful marks

About Me

My name is Steve, I am 39, and I was D fairly atypical in that I moved on to acce DX. I would rather not have ALS, but I h does any good and I choose not to waste lamenting what I no longer can do. On th challenges and take a great deal of satis losses. I am disturbed that so few pALS efforts to create a residential pALS co-op environment such that pALS choose life i

 1326 Views

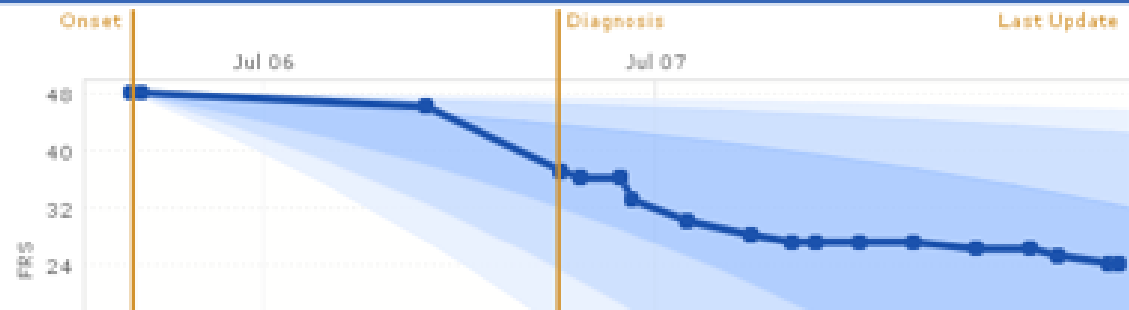
 ALS Public Registry

ALS Condition

FRS: 24
(latest: 03/07/08)

Progression rate
percentile

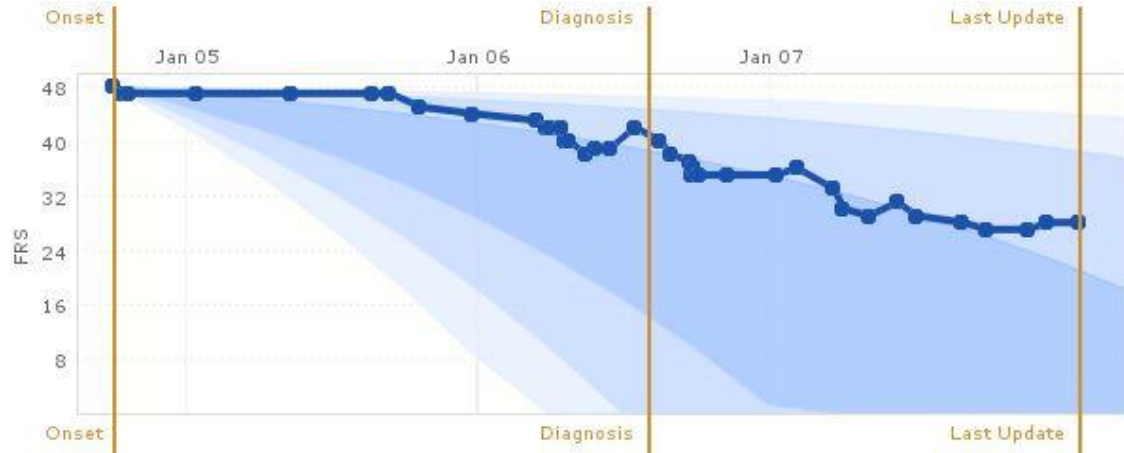
-  5-10th (rapid)
-  10-25th
-  25-75th (average)



FRS: 28
(latest: 01/22/08)

Progression rate percentile

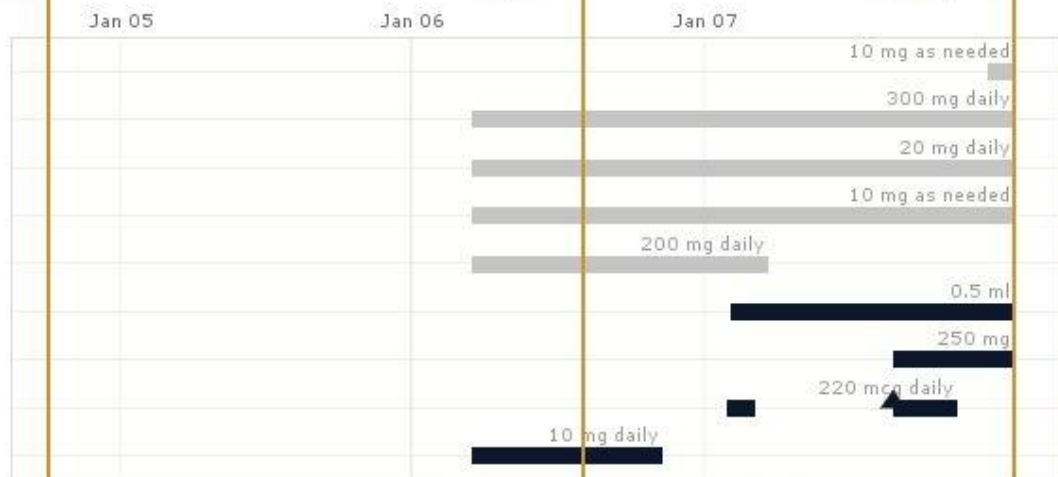
- 5-10th (rapid)
- 10-25th
- 25-75th (average)
- 75-90th
- 90-95th (slow)



Prescription Drug

Reasons Taken

- slow my ALS progress
- general health
- specific symptom
- other



Primary Symptoms

Severity of Symptoms

- none
- mild
- moderate
- severe



Filter Patients By...

Filter Patients

[Reset](#)

Type of Onset

- Any (including unknown)
- Bulbar
- Limb
- Breathing

Time Since Onset

- Any (including unknown)
- Less than 2 years
- 2-5 years
- More than 5 years

Severity

- Any (including unknown)
- FRS more than 36
- FRS 36-18
- FRS less than 18

Age Range

- Any (including unknown)
- under 40
- 40-49
- 50-59
- 60-69
- 70 or older

[Summary](#)

[Individuals](#)

[Graph](#)

[Side-Effects](#)

[Map](#)

Timeframe

months before lithium

months after lithium

Limit Patients to

FRS points before lithium

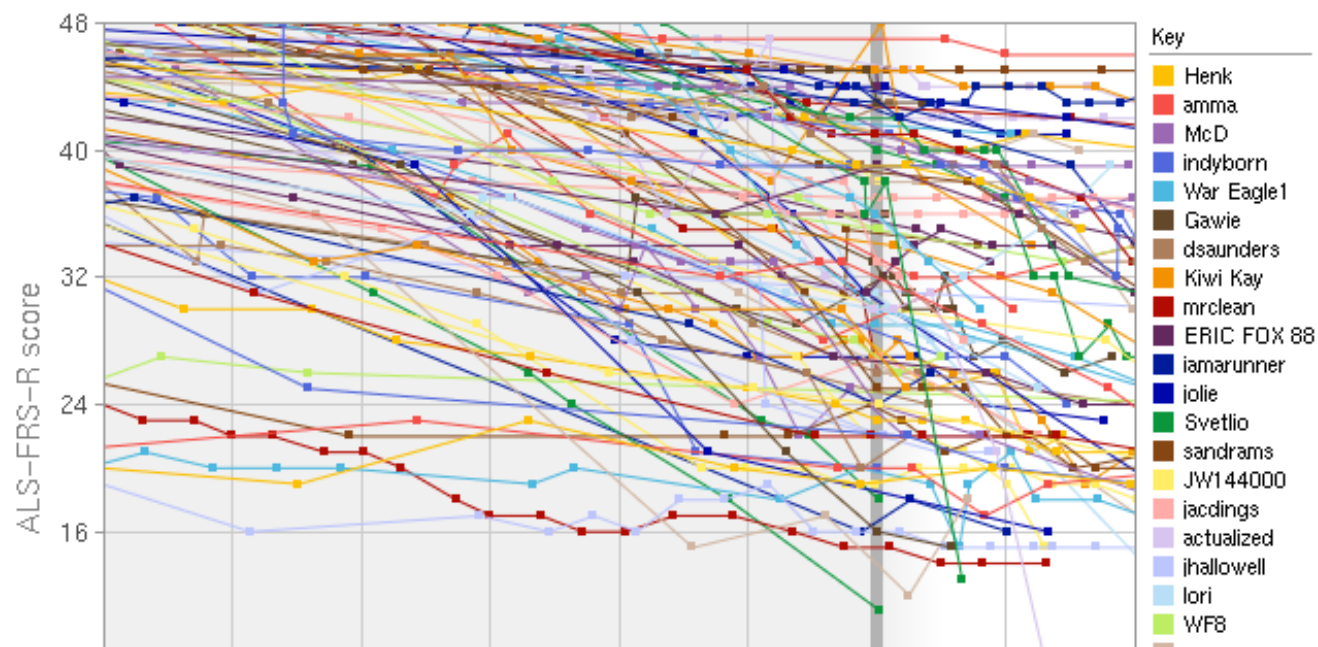
FRS points after lithium

[Update Graph](#)

[Printable Version](#)

Print a copy of this graph.

ALSFRS-R Scores of Patients on Lithium





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17 hours ago

Davec on Royal Albert Edward Infirmary (Accident and emergency)

[“Concern over Balint Groups' use of patient information”](#)

yesterday

susanne on NHS services across the board, especially London region

[“Amazed at the speed of Southend blood clinic”](#)

2 days ago

Julia Alana on Southend Hospital (General surgery)

[“Very good experience at Guernsey House so far”](#)

2 days ago

National award winner



Your opinion

Patients, service users, carers, relatives, friends, staff. This is for everyone...

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Services near you

Find stories about health services near your postcode

Your postcode

Find services for...(optional)

e.g. diabetes or eyes



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Ophthalmology at Rotherham District General Hospital

[56 opinions](#)

Key to ratings

How other people rated this service	◆◆◆◆◆ (from 58 ratings)
Standard of medical care	◆◆◆◆◆
Standard of nursing care	◆◆◆◆◆
Cleanliness	◆◆◆◆◆
Parking	◆◆◆◆◆
Treated with respect and dignity	◆◆◆◆◆
Information and decision making shared appropriately	◆◆◆◆◆
Service punctuality/timeliness	◆◆◆◆◆

Other services at this site

This service is provided at
[Rotherham District General Hospital](#)

Tell us what you think:

Share your story

Further information

Patient Advice and Liaison Services (PALS)

tel: 01709 307646 or

email: pals@rothgen.nhs.uk

You can talk to PALS who provide confidential advice and support to patients, families and their carers, and can provide information on the NHS and health related matters.



What do we know about the impact of accessing health information on the web?

- Does accessing information improve the quality of decision making?
- How does the 'crowd' or 'social media' influence decision making?
- How well can consumers make judgments about what they find on the web?

Study 1: Impact of information access on consumers



Search

Select a Profile	Enter Keywords
<ul style="list-style-type: none">A-DiagnosisA-Drug InfoA-EtiologyA-Patient EduA-Treatment	Disease <input type="text" value="asthma"/> Builder
	Drug <input type="text"/>
	Symptoms <input type="text"/>
	Others <input type="text" value="children"/> Builder
	Save As (Optional) <input type="text"/>

Clear All **Go**

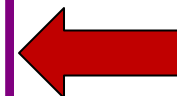
On-line evidence and decision making

- STUDY 1: 75 **clinicians** - 26 hospital doctors, 18 GPs, 31 clinical nurse consultants) *J Am Med Inform Assoc 2005; 12: 315-321*
- Answer 8 medical problems
- Decision accuracy: **21% improvement**
 - Pre-search: 29% correct
 - Post-search: 50% correct

- STUDY 2: 227 **consumers** *J Med Internet Res 2008;10(1):e2*
- Answer 6 consumer health questions
- Decision accuracy: **20.8 % improvement**
 - Pre-search: 61.2% correct
 - Post-search: 82% correct

Errors and confidence

Consumers' responses		% (95% CI)	Increased confidence post search
Pre-test	Post-test		
<i>Wrong</i>	<i>Wrong</i>	13.3% (11.2-15.6)	51.9% (42.5-61.0)
<i>Wrong</i>	<i>Right</i>	25.5% (22.8-28.4)	54.0% (46.3-61.6)
<i>Right</i>	<i>Wrong</i>	4.7% (3.6-6.3)	40.4% (27.6-54.7)
<i>Right</i>	<i>Right</i>	56.5% (53.3-59.6)	71.1% (67.4-74.6)



J Med Internet Res 2008;10(1):e2

Study 2: Impact of the crowd on consumer decisions



Scenario 5.4: What did others think?

What did others think?

Total number of people: 167

Yes: 19% (33 people)

No: 58% (98 people)

Conflicting evidence: 16% (27 people)

Don't know: 5% (9 people)

Your answers are:

Before searching: Don't know

After searching: Yes

You have a chance to answer the question again...

We hear of people going on low carbohydrate and high protein diets, such as the Atkins diet, to lose weight.

1. Is there evidence to support that low carbohydrate, high protein diets result in greater long-term weight loss than conventional low energy, low fat diets?

- Yes
- No
- Conflicting evidence
- Don't know

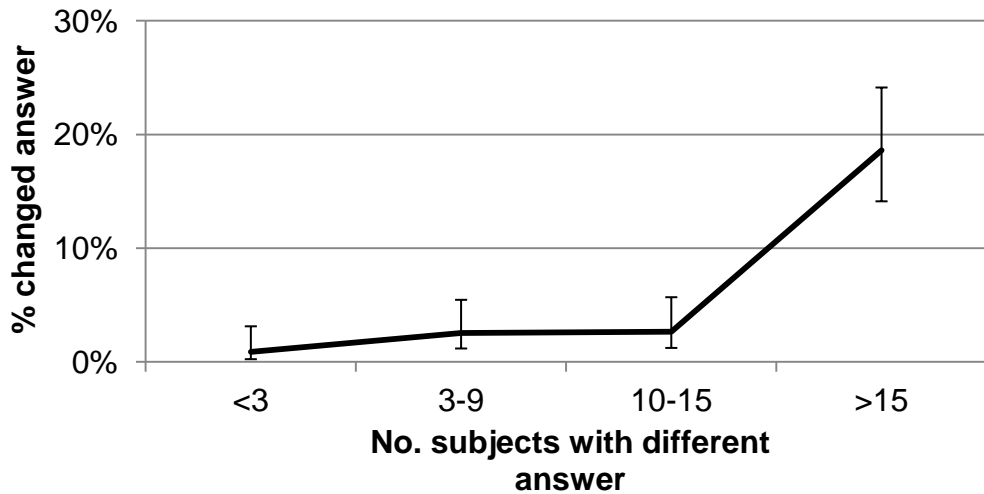
Next

Consumers who were **not as confident in their post-search answers ...**

were 28.5% more likely to change their answer after feedback ...

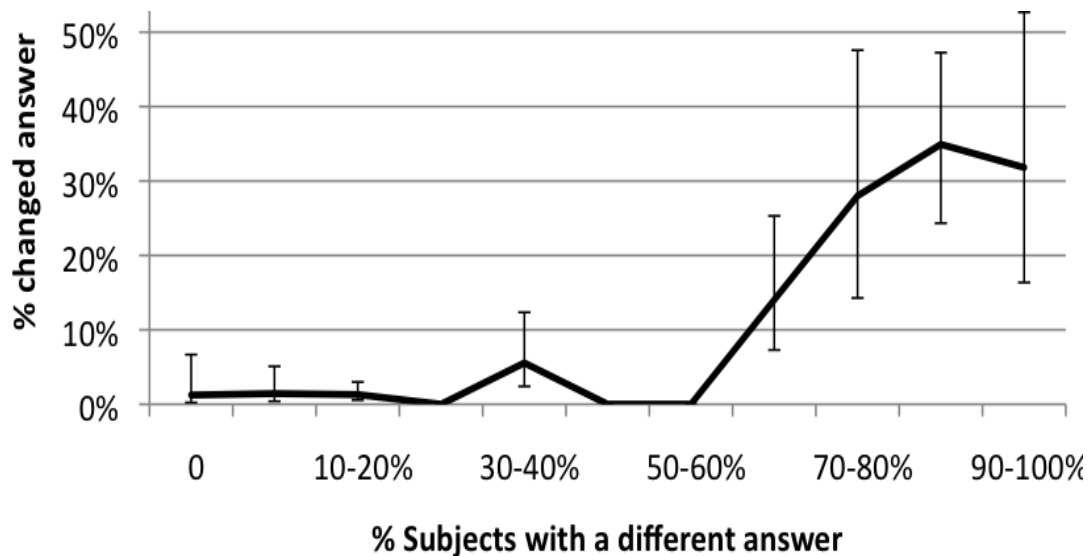
than those who were confident or very confident with other subjects answers ($P < 0.001$)

J Med Internet Res 2008;10(1):e2



Opinion volume

people are more likely to change views the more people hold a different view

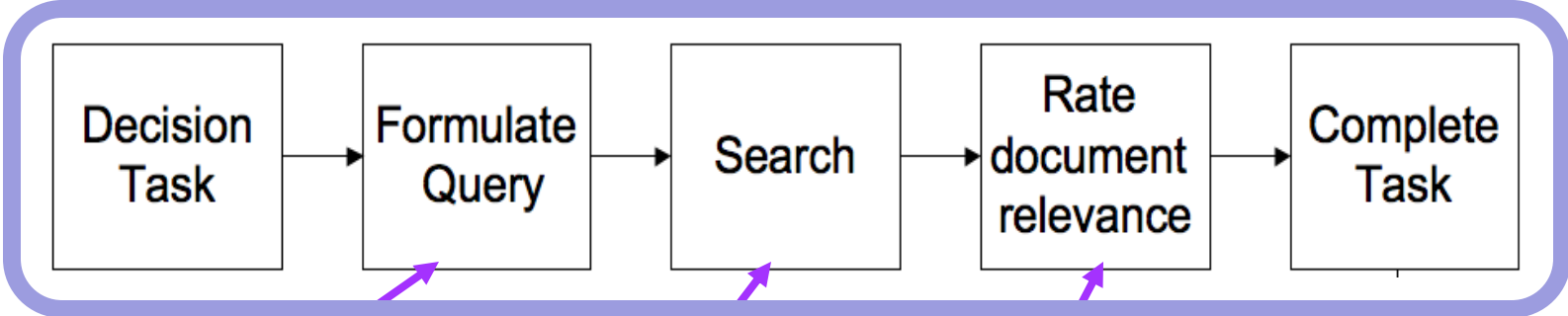


Opinion density

people are more likely to change views the greater the proportion of a group hold a different view

Medinfo 2010 (to appear)

Where can we act to improve decision making?



HEALTHY.me

PERSONAL RECORD
Record and keep track of all your medical tests in one place.

PILLBOX
Know exactly what medication to take at certain times of your journey.

TEAM
Keep a record of all your contacts throughout your medical journey.




SCHEDULE
Monitor all of your scheduled tasks and appointments quickly and easily.

My Pillbox

Browse through your medications below.

PILLBOX

Add Pill

	MEDICATION	ROUTE	AMOUNT	FREQUENCY	START DATE	STOP DATE	COMMENTS	USAGE
	Folate or Folic acid (400 ug)	Oral	As instructed	Once daily				Take <small>View history</small>
	Analgesia	Oral	Follow instructions on the packaging	As required	Orientation visit	Pregnancy test		Take <small>View history</small>
	Pregnyl (1500iu)	Injection		Day 3, 6 & 9 following egg & sperm collection (Day 0)				Take <small>View history</small>

My Personal record > Procedures

Browse through your procedures below

(Note: for new procedures, add them from the journey page)

PERSONAL
RECORD

	PROCEDURE	CLINICIAN	LOCATION	DATE & TIME	RESULTS	COMMENTS
	Egg Collection (day surgery)		IVF Australia clinic	NA	Fertilised Collected Matured Divided	Here are my instructions on what to do with unused fertilised eggs (as stated in the consent form):...
	Egg Collection (day surgery)		IVF Australia clinic	NA	Transferred Frozen	
	Pregnancy test		IVF Australia clinic	NA		Do not take home pregnancy tests
	Ultrasound of foetus		IVF Australia clinic	NA	Heartbeat: Y/N #sacs Gestational score (mm3)	
	Post-cycle discussion	Your fertility specialist	IVF Australia clinic	NA		



My Schedule > Edit Schedule

Edit details for this appointment in your Schedule

[Save](#)[Cancel](#)[Delete](#)

SCHEDULE

DATE

TIME

TASK

Su	Mo	Tu	We	Th	Fr	Sa
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

LOCATION

REMINDER number of hours before

TO DO



My Team

Browse through your contacts below



TEAM

[Add Team Member](#)

	NAME	ROLE	LOCATION	CONTACT DETAILS
	May	Nurse	IVF Australia	(02) 9999 2222
	sarah	friend		

Example in in-vitro fertilization (IVF)

- IVF cycle: Agonist (Long Down Regulation)
- Duration: 8 weeks from Oct 2009 to Jan 2010
- Region: Urban Australia
- Participants: 17 recruited, 14 completed

The IVF Journey

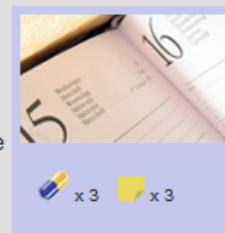
Click 'Add' to add items into your profile

Add

Click on a stage to find out more

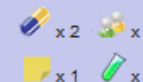
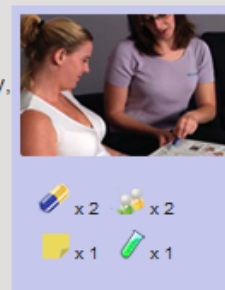
1. Stage 1 - Make appointment

- The first step in the IVF treatment journey is **making a phone call** to book an appointment with a clinic nurse. Over the phone, the nurse will ask you questions and may make some recommendations for you before you attend the appointment. Up until the time of your visit you should continue to follow any health or lifestyle guidelines that might help improve your chances of conception. This information is available through the IVF Australia website.



2. Stage 2 - Orientation visit

- At the **orientation visit** you will be provided with a lot of information about IVF treatment. It is recommended that both you and your partner attend the orientation. The amount of information covered in the first visit might be overwhelming at first. Don't worry, the IVF staff are there to help and can be contacted if you have any questions or concerns throughout the course of your treatment.



3. Stage 3 - Treatment starts

The IVF Journey

Add

Supplements and pain relief

Folic acid and other supplements may be helpful in preparing the body for a healthy pregnancy. If you are taking folic acid, vitamins or other supplements, add them to your pillbox.



1. At each stage of your IVF cycle, you'll find the medications you are likely to take...

PILLBOX

FOLIC ACID

Folate or Folic acid, a B vitamin helps prevent birth defects of the brain and spinal cord when taken before and very early during pregnancy.

ADOPTED / RECOMMENDED	MEDICATION	ROUTE	AMOUNT	FREQUENCY	START TIME	STOP TIME	COMMENTS
	Folate or Folic acid (400 ug)						Folic acid, a ...

2...the appointments you'll need to keep track of...

SCHEDULE

ORIENTATION VISIT

Create a reminder for your orientation visit

ADOPTED / RECOMMENDED	TASK	LOCATION	DATE	TIME	REMINDER	TO DO
Adopted	Attend Orientation visit	IVF Australia	About day 22 of menstrual cycle	AM	One day beforehand	Before the visit...

At the start of your treatment, you may feel a bit overwhelmed at first. Don't worry, the IVF staff are here to help and can be contacted if you have any questions or concerns throughout the course of your treatment.

3....the people looking after you...



TEAM

NURSE

An IVF Australia clinician will take you through your initial orientation visit. They will be available to answer any questions you may have.

ADOPTED / RECOMMENDED	NAME	ROLE	LOCATION	CONTACT DETAILS	COMMENTS
Adopted		Nurse	IVF Australia clinic		

A blood test will be carried out during your orientation visit. This is the first in a series of blood tests you will have over the next few weeks. You can keep track of the results in your personal record.

4....as well as the tests and procedures you'll need to take...



PERSONAL RECORD

1ST BLOOD TEST

The blood test conducted on this day is to determine your progesterone level, which reveals if you have ovulated.

ADOPTED / RECOMMENDED	BLOOD TEST RESULTS	ESTRADIOL (E2) (PMOL/L)	LUTEINIZING HORMONE (LH) (MIU/ML)	PROGESTERONE (HML/L)	FOLLICLE STIMULATING HORMONE (FSH) (MIU/ML)	HCG
Adopted	First test (DD/MM/YY)		Expected value: < 10	Expected value: > 15		

What will you do with these new systems?

- New journeys : Advance care directives, my loved one is on a ventilator ...
- Family self-support groups
- Communicate with relatives
- Follow-up long term by accessing longitudinal record



Thank you

e.coiera@unsw.edu.au