

Wellcome Trust Public Engagement Fund: proposal from Alec Finlay

Outputs

Structures of Feeling: illustrated paperback book (160pp, 750 copies, £12)

Structures of Feeling: 10 prints and 20 photographic artworks

Artworks donated to Wellcome Collection and Shape Arts Collection

A program of events featuring research scientists, GPs and PWME

A free downloadable PDF offering a description of ME by PWME

Partner organisations

ME clinical research group, London School of Hygiene & Tropical Medicine

Institute of Genetics and Molecular Medicine, University of Edinburgh

Medical research, University of Manchester

Norwich Medical School, University of East Anglia

Clinical Professor of Ageing and Medicine, University of Newcastle

ME Biobank

This pdf gives examples of relevant work referred to in the proposal. Below are other links to Alec's work and other key partners

<http://www.alecfinlay.com/>

www.fvu.co.uk/projects/vocable-orchard-hrv

www.alecfinlay-today.com

<http://www.the-bee-bole.com/>

<http://skying-blog.blogspot.com/>

<http://alecfinlayblog.blogspot.com/2013/11/memorial-remembrancing.html>

Outcomes

Empower PWME

Contribute to PWME's understanding of current research

Model a patient-led initiative improving perceptions of ME

Encourage research

Make a positive case for medical science to PWME

Improve clinician/GP-patient relationships

Challenge stigma

Collaborators

Dr Chris Ponting

Prof Julia Newton

Prof Tom Shakespeare

Dr Keith Geraghty

Dr Luis Nacul

Hannah Devereux

Juliet Chenery-Robson

Marion Michell

Edmund Hardy

StudioLR

PWME

<https://www.ed.ac.uk/profile/chris-ponting>

www.uea.ac.uk/medicine/people/profile/tom-shakespeare

<https://www.research.manchester.ac.uk/portal/keith.geraghty.html>

<https://cureme.lshtm.ac.uk/the-uk-mecfs-biobank/>

www.hannahdevereux.com

www.julietchenery-robson.com

www.supinesublime.wordpress.com

<https://edmundhardy.org/complex-crosses/>

www.studiolr.com

Collaborators

Dr Chris Ponting (University of Edinburgh): specialist in causes of autoimmune diseases such as ME; AF will collaborate with Ponting to visualise research data on genetics and ME. Their conclusions will be communicated creatively, clearly and accessibly in the publication, artist blog and at a public in conversation (Edinburgh).
<https://www.ed.ac.uk/profile/chris-ponting>

Prof Julia Newton (University of Newcastle): specialist in bioenergetic dysfunction in ME; AF will collaborate with Newton in terms of visualising research data on fatigue and comparing the data with AF's text composed of PWME's descriptions of their symptomology. Their conclusions will be communicated creatively, clearly and accessibly in the publication, artist blog and at a public in conversation (Newcastle).

Prof Tom Shakespeare (University of East Anglia): specialist in medical ethics and perceptions of disability; AF will collaborate with Shakespeare in a discussion of perceptions of ME in the context of historical parallels with other conditions where debate or stigma has affected research and treatment. Their conclusions will be communicated creatively, clearly and accessibly in the publication, artist blog and at a public in conversation (Norwich).
www.uea.ac.uk/medicine/people/profile/tom-shakespeare

Dr Keith Geraghty (University of Manchester, and ME clinical research group, London School of Hygiene and Tropical Medicine): specialist in efficacy of treatments for ME, including CBT, exercise therapies, and bio-medical approaches; Geraghty will collaborate with AF in terms of visualising data relating to ME, and discussing ways in which this research and AF's text composed of PWME's descriptions of their symptomology can improve the GP-patient relationship. Their conclusions will be communicated creatively, clearly and accessibly in the publication, artist blog and at a public in conversation (London).
<https://www.research.manchester.ac.uk/portal/keith.geraghty.html>

Dr Luis Nacul (GP, London): general practitioner and Co-Principal Investigator (Clinical) at ME Biobank; collaborated with Geraghty on biomedical approaches to ME; AF will participate in the ME biobank.
<https://cureme.lshtm.ac.uk/the-uk-mecfs-biobank/>

Hannah Devereux, photographer who has collaborated with Alec on healthcare projects; Hannah has a chronic illness. Her photographs of researchers at work, ME testing conducted on AF, and 'blanket landscapes', portraying the domestic space of illness as it is experienced by people with ME will be included in the publication, artist blog, shown at public in conversations, exhibited, and a selection of images donated to Shape Arts Collection. Previous examples of similar images are include below.
www.hannahdevereux.com

Juliet Chenery Robson, photographer, has made a body of photographic work depicting the experience of PWME will be included in the publication, artist blog, shown at public in conversations, exhibited, and a selection of images donated to Shape Arts Collection. Currently working with Newcastle University EngageFMS funding on a short scoping project to explore the visualisation of ageing related multimorbidity.
www.julietchenery-robson.com

Marion Michell, writer and artist with long term ME; she has written a booklet and artist blog of visual texts and poems describing the symptoms and experiences of a PWME. A new essay will be included in the publication, along with visual texts included on artist blog, shown at public in conversations, and a selection of images donated to Shape Arts Collection.
www.supinesublime.wordpress.com

Text 01: Alec Finlay, Initial texts for *Structure of Feeling*

Composed from texts sourced from three people with long term ME. Note, if this funding application is successful the intention is to use a questionnaire to gather detailed descriptions of ME; this initial text is not necessarily typical of the final text, which will focus more on symptoms.

there is a danger in attributing meaning
to the misfortune of illness –

this will make me a better person
pain is ennobling
no, no, no –

we are the innocent victims of our
own genetic disposition

*

rest – who in their right
mind would call this
rest – it's combat
endurance, anguish,
and affliction

as constricting as irons
and all we can do
is wait it out in our beds

*

you always try to
carry a line
just ahead of you

so as to not cross
into all the pain
that follows

*

things caught in glimpses
in however long it takes
to forget about the city

I can no longer walk
my hometown map
streets lost from memory

where I used to row boats
where I learned to ride a bike
tall fences and downhill roads

what are the birds doing without me?
I go home the long way
unblown by the wind

*

I'm too unwell
to be in a car
or even outside

no wheelchair
no glasses dark enough
no mask surgical enough

*

a cryptic condition: *ME*

Text 02: Alec Finlay, poems from *a better tale to tell* (2015)

Composed from submissions to the Smith Commission which followed the 2014 Referendum. This section of Alec's book-length poem relates to healthcare and social services. This a found poem composed from numerous contributors, all anonymous; no words have been altered by Alec, only lineated. The book is an example of how an artist can create healing and resolution from situations of social conflict, by representing diverse opinions in a truthful way.

I was born in
the South East of England

welfare needs
to be dealt with
where we at least care

I can't begin
to tell you
of the anguish
we undergo

I wonder
what happens
to those
with no-one

I became disabled
in adulthood

about our most
vulnerable

on behalf of a son
who has had
a lifetime of pain

to help them?

I have found Scotland
far more welcoming
than England

changes
to welfare benefits
are mentally
taxing people

values
are to do with
the moral life

which now sadly
has a culture
of vilifying

to have him
harangued
by the DWP

experienced
in companionship
with other people

disability and
disadvantage

to breaking
point

while they cut off
his payments
for months

that language and view
of people on benefits
as 'scroungers

as the parents
of a seriously disabled
young adult

leaving him humiliated
dependent on hand-
outs from relations

they are not derived
from a nationalist
or unionist
lexicon

is largely unwelcome
here

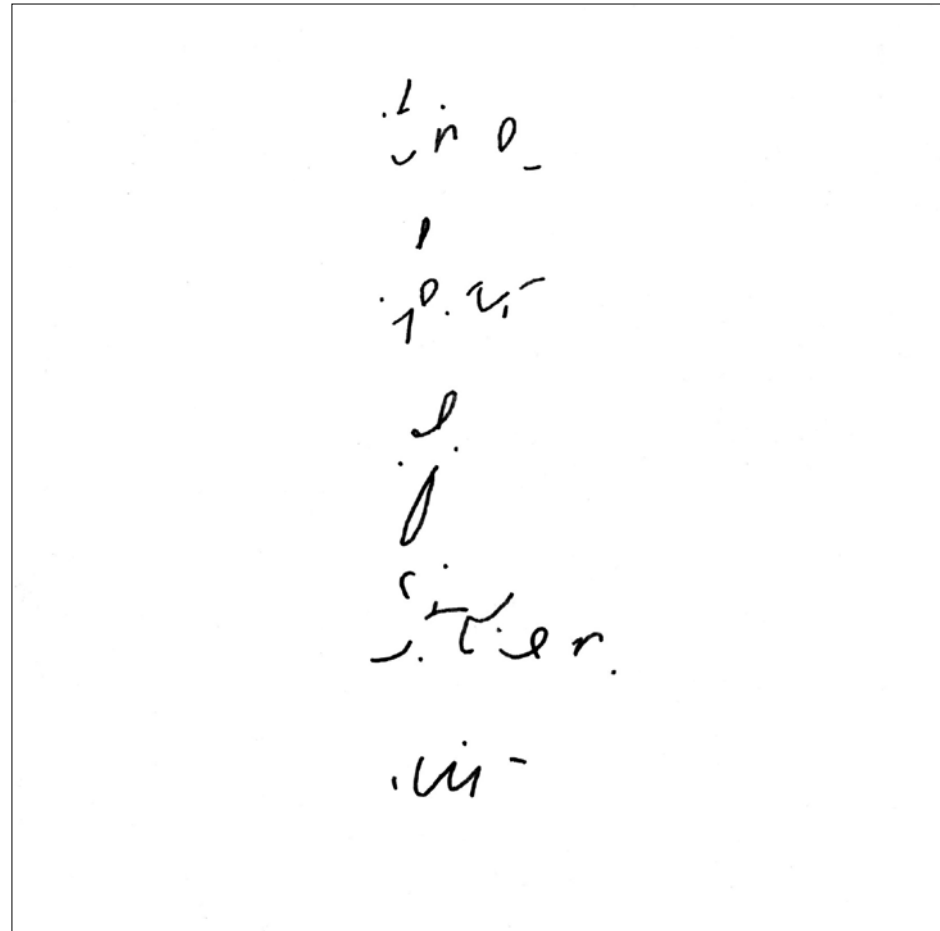
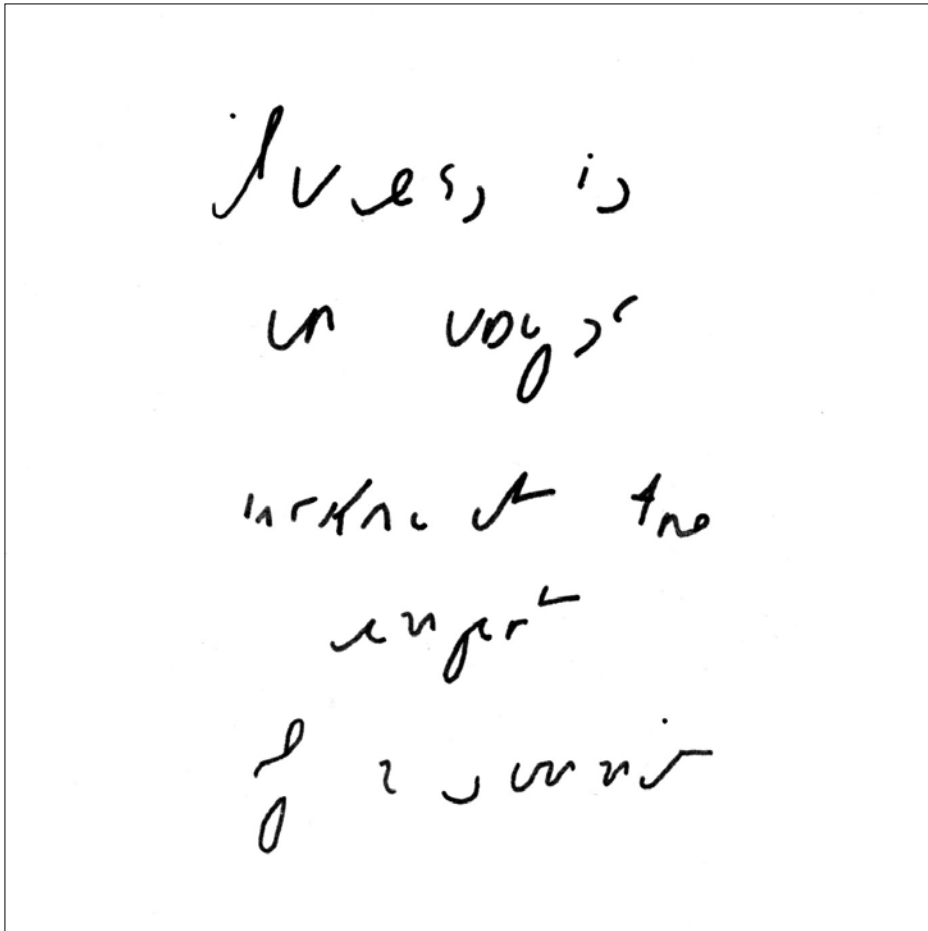


Image 01: *Structure of Feeling*: erased text

These poem-images were created by Alec Finlay as preliminary research for *Structures of Feeling*. It uses testimony from a PWME and then partially erases the letters, to suggest the complexity of diagnosis in a medical context, and the difficulties PWME experience in terms of the public (mis-)perception of their illness, and their own sense of disappearing from the life they once had.

Such touching images will be juxtaposed with the more formal and diagrammatic prints which visualise data derived from medical research into ME.



Image 02: Alec Finlay, with Hannah Devereux, ‘Counterpane landscape’ from *a far-off land*, for MacMillan Cancer Support Arbroath (2017-18)

These photographs by Hannah Devereux were conceived by Alec Finlay and inspired by RL Stevenson’s famous poem of childhood, ‘The Land of Counterpane’, in which bedding becomes an imaginary landscape of hill and dale in the child’s imagination.

For people living with severe ME the ‘landscape’ of domestic space and, in particular, the bed, becomes a place of rest, retreat and suffering. In *Structures of Feeling* Devereux and Finlay will develop further iterations of this revealing symbolic landscape in consultation with PWME.



Image 03: Alec Finlay, *a far-off land*, an installation for MacMillan Cancer Support Arbroath (2017-18)

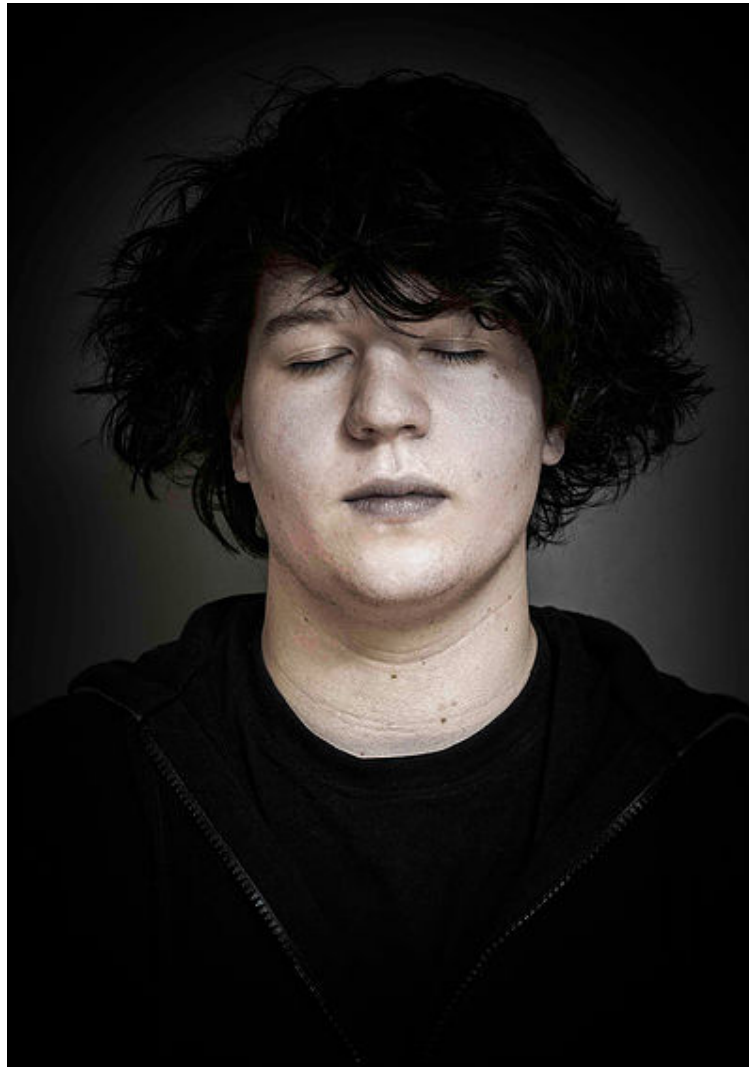


Image 04: Juliet Chenery-Robson, *Portrait of an Invisible Illness*

Chenery-Robson produced this series of images in collaboration with Professor Julia Newton, Clinical Professor of Ageing and Medicine, University of Newcastle, whose research into fatigue and ME will feature in *Structures of Feeling*. A selection of these images would be included in the book. They are a moving testimony to the suffering experienced by individuals. I have spoken to clinicians who find them highly effective in communicating the condition.

www.julietchenery-robson.com

vocable-orchard (HRV) | for Kurt Schwitters
a phylogenetic recomposition of the avant-garde

Alec Finlay
with Dr. Simon Park (HRV), Lawrence Upton (vocables), and StudioLR (design)

Die Wut des Niesens

Tesch
Haisch
Tschiaa
Haisch
Tschiaa
Haisch
Haisch
Happaisch
Happapepaisch
Happapepaisch
Happapepaisch

Kurt Schwitters
The Rage of Sneezing (1946)

Human Rhino Virus (HRV) is composed of a long thread of RNA surrounded by a protein shell. These proteins can be visualised as chains of 20 amino acids, represented by letters.

G P A V L I M C F Y W H K R Q N E D S T

Proteins carry out some of the functions necessary for virus replication. The RNA is converted into a large single polypeptide, 2150 letters long, that divides into 12 sections. Here Kurt Schwitters's poem-score of a sneeze, 'Die Wut des Niesens' (1946) has been recomposed as 20 vocable sounds, and these have then been processed via the RNA of the common cold, HRV.

CHAIN 12 (RNA-directed RNA polymerase 3D-POL)

ahh ora rng oor arr hey rch rch oor hey àhr
reh àrr arr ann hey rng tsc oor ann reh rch
oor rch arr ora ann hey eer aar ehr yeh eer
aar ann ahh hey rch àhr ann aaa eer arr hey
àhr rch yeh aaa eef arr ora eer yeh aar àrr
àhr aaa arr aar hey rch ehr rch ahh àrr oor
yeh reh hey rng àrr yeh tsc rng eef rng aaa
hey hey tsc ehr aaa aaa ora arr rng oor arr
yeh rng yeh ann rch ann rng oor arr àhr yeh
hey eer aar ahh oor yeh ahh arr àhr aaa arr
yeh arr àrr oor hey aaa ahh aar ann ehr rng
aaa rah ahh eer rch rch eef yeh arr rng àrr
àrr rch oor rch yeh rng hey rch arr rch àhr
aaa rng yeh rch ehr ahh eer yeh arr ann rah
eer oor aar arr rch yeh àhr arr eef rch tsc
àhr rch eer rng rch ahh rch oor eef eer rng
àhr aaa hey hey eer àrr yeh oor arr arr aar
eef oor oor aar ahh àrr arr aar hey rch aar
tsc arr àrr ann ahh rng eer oor ahh hey aaa
eer ahh reh yeh ann àhr eer aar ehk hey rch
rng ann aaa rah arr yeh yeh rch reh rng rah
aaa aar yeh ehr oor àrr ehr yeh ahh hey rng
tsc ann rng ehk aar àhr aaa arr rch ora eer
arr eer yeh arr hey aar àrr ann oor arr rng
yeh eef arr reh rch hey rch tsc rng aar rch
àrr oor ehr ehr àhr eer àhr ahh ahh eer ann
hey ahh reh hey ahh oor hey rng aar àrr oor
rah rng àrr àrr rng rng rng eef oor arr eer
arr yeh aaa ehr rch àrr rng yeh arr yeh rch
arr rch rng rng aaa ehr ahh yeh yeh eer rng
aar hey ehr rng tsc àhr arr yeh rah àhr aaa
rng aaa rng àhr ahh eer rch ehr ahh arr oor
rng oor ann aaa yeh rch hey àrr oor aar eer
rch arr yeh ehr hey àrr eer oor aar arr rch
eef ahh aar rch ora yeh àhr rch ehr àrr aar
arr rng tsc ann oor aar ann àhr yeh àhr rng
aar àhr hey rng eef ehk oor rch rch ann hey
ora rah tsc àhr tsc eer arr hey arr reh tsc
arr rah ehk tsc àrr ahh eef yeh aaa ehr rch
rch aar eer àhr rch rng eef hey eer hey aaa
ahh eef aaa arr ehr rng ann ann ehr yeh arr
arr arr tsc àhr ehk ehr àhr rch aar

G Q I T L S K K T S E
C N L P S I H T P C K
T K L Q P S V F Y D V
F P G S K E P A V L S
E K D A R L Q V D F N
E A L F S K Y K G N T
D C S I N D H I R I A
S S H Y A A Q L I T L
D I D P K P I T L E D
S V F G T D G L E A L
D L N T S A G F P Y I
A M G V K K R D L I N
N K T K D I S K L K E
A I D K Y G V D L P M
V T F L K D E L R K H
E K V I K G K T R V I
E A S S V N D T L L F
R T T F G N L F S K F
H L N P G I V T G S A
V G C D P E V F W S K
I P A M L D D K C I M
A F D Y T N Y D G S I
H P I W F E A L K Q V
L V D L S F N P T L I
D R L C K S K H I F K
N T Y Y E V E G G V P
S G C S G T S I F N T
M I N N I I R T L V
L D A Y K N I D L D K
L K I I A Y G D D V I
F S Y I H E L D M E A
I A I E G V K Y G L T
I T P A D K S N T F V
K L D Y S N V T F L K
R G F K Q D E K Y N F
L I H P T F P E D E I
F E S I R W T K K P S
Q M H E H V L S L C H
L M W H N G R D A Y K
K F V E K I R S V S A
G R A L Y I P P Y D L
L L H E W Y E K F

Image 05: Alec Finlay, *vocable-orchard (HRV)* (2013)

This poetic score and digital animation represents RNA. It was created in collaboration with the molecular microbiologist Dr. Simon Park (University of Surrey). It is inspired by Kurt Schwitters' sound poem ('Niessscherzo', 'Sneeze Scherzo', 1936), which Alec updated, by reprocessing the original text – a transcription of a sneeze – via the RNA code of human rhinovirus (HRV). The vocables in the sneeze transcription (see following page) and RNA are both composed of strings of letters and, given this common basis, Alec devised a procedure based on pairing which had the effect of magnifying Schwitters' score, 'virally', into the massive scale of molecular detail. This translation brings the original poem up to date in terms of contemporary scientific understanding. These artworks will inform the print visualisations of data Alec produces in collaboration with scientists.

A
H H

R
G N

E
H H

A
P R

A
N N

R
A H

T
S C

A
H R

A
A A

R
H E

R
H C

Y
H E

E
E R

A
A R

E
E F

H
E Y

A
P R

E
E R

O
P A

O
O R



Image 06: *Taigh*, National Memorial for Organ and Tissue Donors, Royal Botanic Gardens Edinburgh (2014)

Alec uses experiences of illness empathetically. He's never made work about ME, which he contracted aged 21, via glandular fever. His mother, Sue Finlay, had ME from when he was twelve. He volunteered for ME trials at the Sports Sciences department, University of Newcastle, undergoing exhausting tests designed to measure the effects of fatigue on comprehension, comparing high performing athletes with PWME who have ME.

These photos show the National Memorial for Organ and Tissue Donation, in a peaceful area of the Royal Botanic Garden Edinburgh, selected and designed by Alec. The top image shows a wooden box containing a memorial book into which Alec copied the first name of every donor, along with some medicine that is taken by an organ recipient, and a scalpel, to remind the viewer of the medical expertise that makes the secular miracle of donation possible. Dr Gavin Francis, who wrote about the memorial, reports that a number of people volunteered to donate a kidney after reading about Alec's work.

Alec also published a book for the organ and tissue memorial; at an annual national event he makes a speech and presents copies to families whose loved one's were donors – a profoundly moving experience. *Structures of Feeling* will have a similar healing effect at a time when ME remains contested.

<http://alecfinlayblog.blogspot.com/2013/11/memorial-remembrancing.html>



p P a A r l t N s

Alec Finlay

Y E S T E
R D A Y T
O D A Y A
N D T O M
O R R O W

Alec Finlay

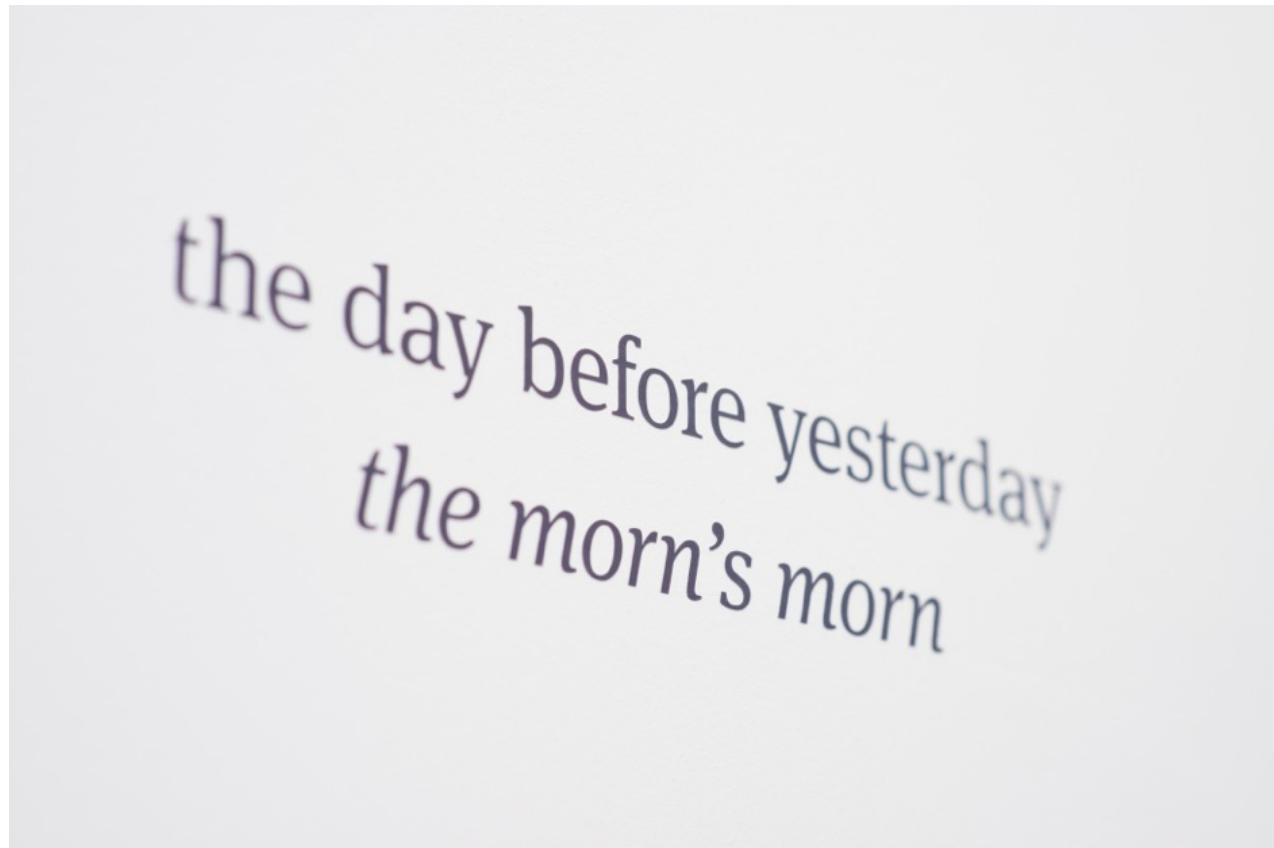
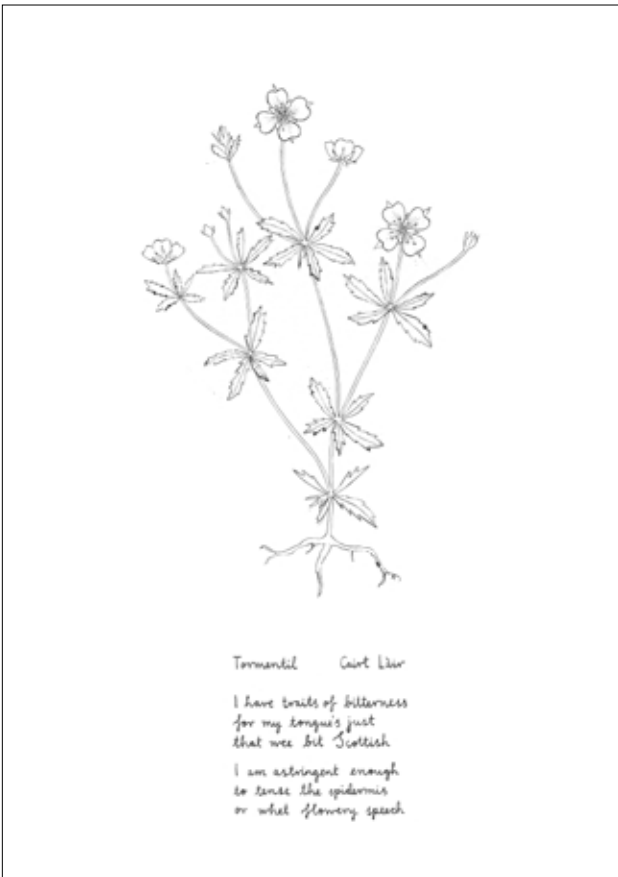


Image 07: *today today today*, 2013, (2013), a digital animation, artist blog and booklet for Beatson West of Scotland Cancer Centre, Glasgow (top left)

Image: Alec Finlay, with Ken Cockburn, *forty couplets*, 2012, for Aberdeen Royal Infirmary (above)

Image: Alec Finlay, with Hanna Tuulikki, *100 flowers*, for Queen Elizabeth University Hospital (left)

These images illustrate some of Alec's previous healthcare projects made for installation in hospitals or as publications to give free to patients. The small poem-cards were used on blog (). The handwriting suggests the vulnerability of illness, and the poems simple forms suggest a day-book. The symbolism of the word "today" runs through these poems, which were gathered into a booklet. The flora and accompanying poems were produced as a series of ten poem-prints for Queen Elizabeth University Hospital, Glasgow (Ginkgo Projects, 2015). They describe the healing effects of flora. The wall text is one of 40 composed for NHS Grampian Hospitals Art Trust, describing the region which the hospital served.

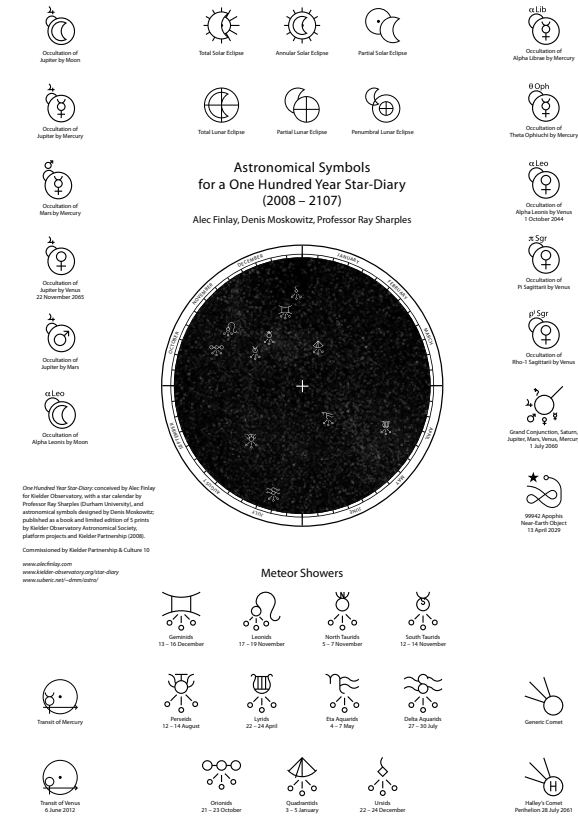


Image 08: Alec Finlay, with Denis Moskowitz & Professor Ray Sharples, *100 Year Star Diary* (2008) (above)

Image: Alec Finlay, beehive for the University of Stirling (top left)

Image: Alec Finlay, text for windmill turbine (left)

Alec has worked on sci-art projects with a wide variety of experts, including apiculturalists, installing beehives with texts on teaching hives at University of Stirling.

Alec collaborated with an astrophysicist on a 100-year Star Diary (prints and book) for Kielder Observatory, where he also created this text painted onto a windmill turbine, connecting the windmill which powers the observatory with the stars.

Poem 25
[elemental]

25
25, 25, 26
26, 26, 27
27, 27, 28
28, 28, 29
31, 33, 35, 37, 39
42, 44, 46, 48, 52
53
9, 9, 9
54
8, 8, 8
55
7, 7, 7
56
6, 6, 6
56
6, 6, 6
 $\frac{3}{4}$ 6
57
5, 5, 5
 $\frac{3}{8}$ 5
58
4, 4, 4
 $\frac{1}{2}$ 4
59
4, 4, 4
 $\frac{1}{2}$ 4
25
4, 4, 4
 $\frac{1}{2}$ 4
4, 4, 4
 $\frac{1}{2}$ 4
4, 4
4
4
4

Nießscherzo
Das Ganze niesen

tesch
haisch
tschiiiaa
pesche püsch
haisch
tschii aa
pesche püsch
haisch
happaisch
hapeschepüsch
happapeschaisch
happe tschaa
happe tschaa

piss püss piss pass
piss puss piss pass
piss püss piss pass

piss puss piss pass
piss püsc pisc pass
piss puse pise pass

piss püsch piss pass
piss pusch piss pass
piss püsch piss pass
piss pusch piss pass

pesche pusch piss pass
pesche püsch piss pass
pesche pusch piss pass
pesche püsch piss pass

piss püss piss pass
piss puss piss pass
piss püss piss pass
piss püss piss pass

tesch
haisch
tschiiiaa
pesche püsch
haisch
tschii aa
pesche püsch
haisch
happaisch
hapeschepüsch
happapeschaisch
happe tschaa
happe tschaa

Image 10: Kurt Schwitters Kurt Schwitters, untitled visual poem, *Ursonate* (1922-32).

Alec's project is inspired by a tradition of Modernist poetry that relates to diagrams, transcription and attempts to represent material or biological processes. Trained in visual poetry and poetic transcription, Alec has written about the relationship between innovative Modernist poetry, visual art, and scientific diagrams/medical graphics. He specialises in graphic and visually innovative texts, books and prints.

On the right, a detail from Kurt Schwitters *Ursonate* – *Sonata in Primeval Sounds* – *Sonata Présyllabique* (1922-32), the most ambitious poetic score of the Modernist era, realised in collaboration with the illustrious typographer Jan Tschichold, who scored the sound clusters in minute detail. Designed in the rational style of the new typography, set in Futura and Garamond with no capital letters, the *Ursonate* appeared as issue 24 of Schwitters' journal *Merz* (1932).

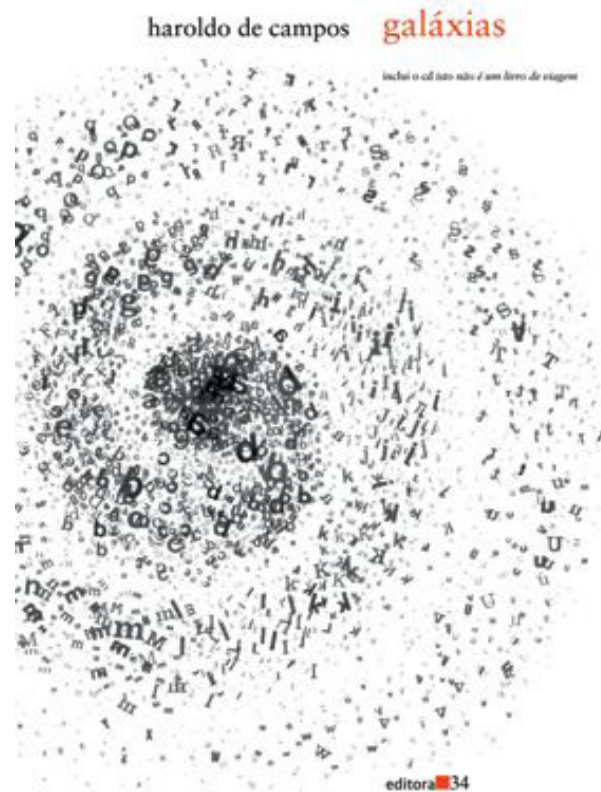


Image: Christian Bok, 'Crystallography'
Image: Haroldo de Campos, 'Galaxias'

As these two exciting images show, the innovative tradition of Modernist poetry is more appropriate for rendering scientific research than the traditional lyric poet's voice. Alec co-edited a popular anthology of visual and Concrete poetry, *The Order of Things*, (pocketbooks, 2002), and has longstanding experience of using such innovative visual forms in public artworks to make complex ideas accessible. The print visualisations of date produced as part of *Structures of Feeling* will be exhibited, displayed at public events, published on the blog and in the book, and donated to two major collections, Wellcome Collection and Shape Arts.

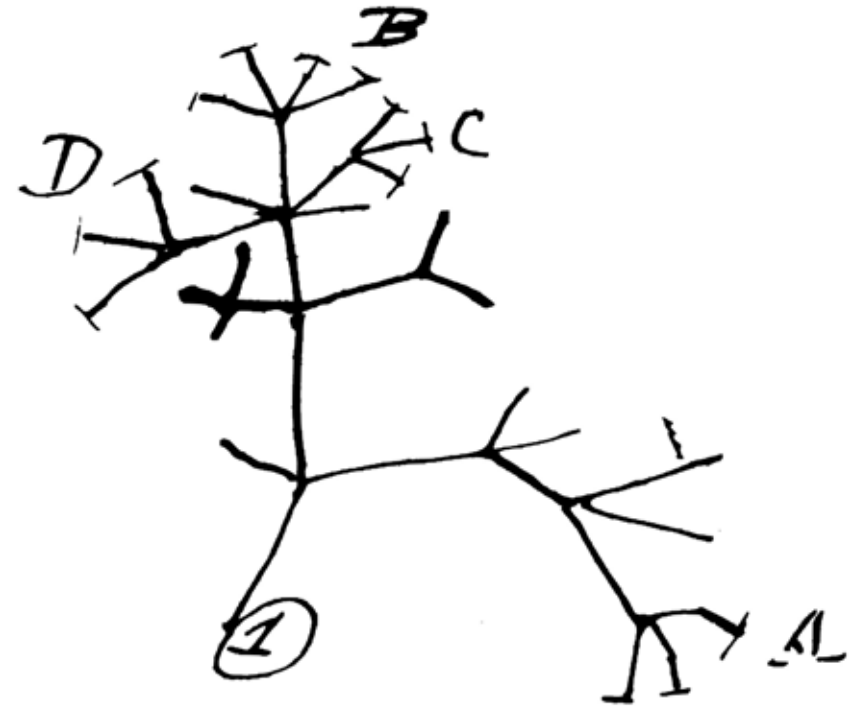


Image: Alec Finlay, *vocable orchard*, 2013 (top left)

Image 11: orchard, photograph by Guy Moreton (left); Charles Darwin, 'Tree of Life' (above)

These final images relating to *vocable-orchard* (HRV) show the tree form used in the animation, in relation to phylogenetic diagrams, connecting Darwin's tree of life to the orchard in Langdale where Schwitters made his final masterpiece (Film & Video Umbrella, 2013). This combination of text, animation, transcription, diagrams, and photography as a means to illustrate complex scientific ideas in an accessible way will inform *Structures of Feeling*.



Image 12: Alec Finlay, with Gill Russell, *th' fleey wud*, phylogenetic diagram of the Upper Teviot (2017) (left)
 Image: Alec Finlay, with Gill Russell, *th' fleey wud*, the Upper Teviot watershed map (2017) (above)

Alec produced the first phylogenetic diagram of a river (Upper Teviot), accompanied by a map. The tree-form of the tributaries are emphasised, and, in the accompanying text, Alec adds the implication that planting trees would aid in flood remediation. In the publication the visualisations are accompanied by place-names and translations to embed local knowledge alongside technical data.

CALA BURN
 WEENS SIKE
 HASS SIKE
 SLITRIG

Cooler Burn
 Wailing Rill
 Gullet Rill
 Cut-a-way River

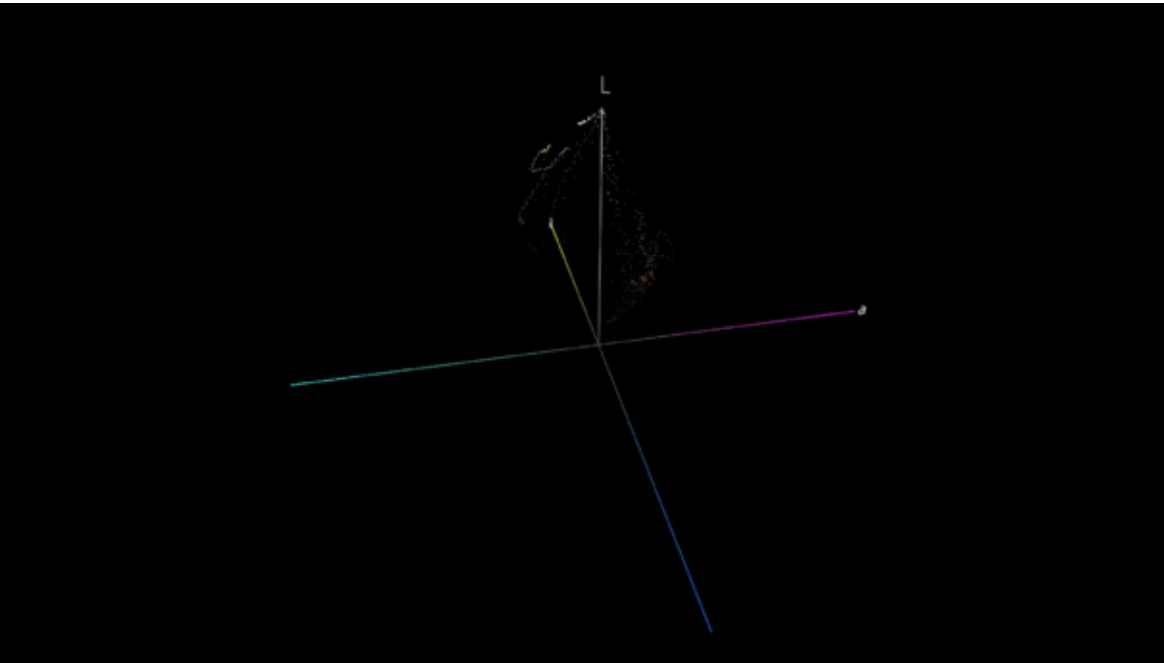


Image: Alec Finlay, Black Tulip (above)

Image: Alec Finlay, Black Tulip, animation (top left)

Image: Black Tulips, photograph by Hannah Devereux (left)



Alec has conceived artworks relating to biodiversity, cryptic colouration, and genetic modification for botanic gardens (Durham, Edinburgh, St Andrews, Chelsea Physic Garden). These images are from an ambitious project relating to black tulips and Tulipomania. The concept is discussed in this extract from an unpublished essay: ‘Schwirrlauf | Tschaa – the evolution of primal motion: The Kurt Schwitters Memorial Lecture, 2014’

‘After Darwin we say, the fittest survive, with a chill. But aesthetics and values also arise in weakness, and flaw, as with the prized black tulip, which originates in a virus spread by an aphid, creating a scion that is ‘broken’, in terms of genetic code. Over generations nature is intensified to produce that rarity, a living black. Such rarities are the subject of financial speculation, breeding contagion, maniacs – the hooded ones, as they were known in Holland – and closed societies which fell victim to ‘Tulipenwoede / Tulipomania’ and the economic crash of 1637.’